La recherche participative
en santé mentale

Bibliographie thématique

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Centre de documentation de l'Irdes

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Synthèses & Bibliographies

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Problématique : la place des malades dans la recherche médicale

La place des malades dans la recherche médicale s'est profondèment modifiée ces dernières années, depuis la « mise à disposition des corps » à la communauté scientique jusqu'à la contribution active des malades qui est prônée actuellement.[1] La participation des usagers à la recherche (dite aussi *recherche-usagère*) s'appuie sur des connaissances ancrées dans l'expérience des services des soins et de la vie avec la maladie et vise des priorités définies par les communautés scientifiques. Les méthodes s'avèrent plus qualitatives que celles de la recherche conventionnelle et même quand elles restent purement quantitatives, les outils reflètent l'expérience des usagers et explorent des thématiques qui leur sont prioritaires.

Le nombre des publications et des travaux sur le thème de la co-recherche avec les usagers a considèrablement augmenté ces dix dernières années. Les premiers écrits datent des années 70 aux Etats-Unis et concernent des groupes de patients atteints du cancer du sein. Les suivants sont apparus dans les pays occidentaux dans les années 80 au moment de l'épidémie de VIH-sida. Les malades ne trouvaient pas de réponse à leurs préoccupations dans les recherches médicales et ont donc demandé de faire partie des protocoles de recherche. Puis les objectifs de la participation des patients en santé se sont précisés et élargis. Usagers, usagers-chercheurs, citoyens… participent à l'évaluation des projets de recherche cliniques, aux comités de recherche et au développement des autorités de santé. Ils s'émancipent [2]pour prendre le contrôle du processus, poursuivre les priorités de recherche des malades, mieux connaître les maladies et éviter toute stigmatisation des patients.

En France, les premiers exemples de participation des patients s'obervent au cours des années 90 dans le domaine du VIH-sida. Les associations d'uagers participent de façon importante aux activités de l'Agence nationale de recherche sur le sida (ANRS). En matière d'évaluation en santé, l'Agence nationale d'accréditation et d'évaluation en santé (ANAES), puis le Haute Autorité de santé (HAS) mettent progressivement en place – notamment depuis la loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de soins – la participation des usagers, des familles et de leurs représentants à chaque étape du processus d'évaluation et d'accréditation des institutions sanitaires.

De nos jours, la participation du patient à la recherche, mais aussi à l'évaluation de l'acte thérapeutique ou de son parcours de soins est donc parfaitement reconnue par la communauté scientifique travaillant en milieu sanitaire et le réel impact de cette pratique est en cours d'analyse. Dans le domaine de la santé mentale, l'étude de cas la plus notoire est le projet Emilia (2005-2010) : *Empowerment et Éducation tout au long de la vie des personnes vivant avec des troubles psychiatriques*. Dans le cadre de ce projet, trois modules de formation à la recherche et à l'intervention ont été proposés à des usagers des services psychiatriques. [3]

L'objectif de cette bibliographie est de recenser les études publiées sur la participation des usagers dans le champ de la santé mentale. Quelques études plus globales sur la recherche participative ont été aussi

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[1] Jouet, E. (2014). La recherche en santé et les patients : de l'utilisation des corps à la contribution active. In : Nouvelles coopérations réflexives en santé : de l'expérience des malades et des professionnels aux partenariats de soins, de formation et de recherche

[2] Defraigne Tardieu G. (2009). L'université populaire Quart Monde. La construction du savoir émancipatoire. Thèse en sciences de l'éducation. Université de Paris 8.

[3] Jouet, E. (2013). "Le projet Emilia : inclusion sociale par la formation des personnes vivant avec un trouble psychique." Savoirs **31**(1)

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identifiées. Les recherches ont été réalisées sur les bases bibliographiques suivantes : Irdes, BDSP, Medline et Ascodocpsy ainsi que sur les portails Cairn et Erudit, pour la période allant de 2007 à nos jours. Cette bibliographie ne prétend pas à l'exhaustivité.

La terminologie la plus souvent utilisée pour désigner la recherche participative dans la littérature française est : recherche participative, *recherche (action) participative, recherche usagère, psychologie communautaire, co-recherche, savoir expérentiel*., patient expert, pair-aidance. Les mots clés interrogés dans Medline pour isoler la littérature étrangère sur le sujet sont les suivants : *patient participation, cooperation behavior, health knowledge attitudes & practice, community based participatory research, user led research, community psychology, empowerment, co-research, patient involvement, expert patient, peer helper, peer support.*

Quelques définitions

Recherche participative, recherche action participative

Le concept de la recherche participative trouve ses racines dans de multiples mouvements. Plusieurs penseurs ont contribué à le façonner, parmi lesquels : Paolo Freire, pédagogue brésilien, notamment autour de la notion d'éducation populaire et de la recherche comme une pratique engagée de solidarité et de soutien ; John Dewey, philosophe étasunien, en référence aux thématiques de pédagogie et d'éducation pour tenter de mettre la science à l'écoute de la pratique, afin que la pratique oriente la science ; Kurt Lewin, psychosociologue étasunien, en liant recherche et changement social. Le terme *participatory research* a été forgé et largement développé au début des années 1970 afin de décrire des processus de création de savoirs au niveau des villages, tout d'abord en Tanzanie puis dans de nombreux autres pays, notamment en Afrique et en Amérique Latine. Le travail combinait l'investigation sociale, l'éducation et l'action dans un processus interdépendant. A partir de 1976 et dans le cadre du Conseil International pour l'Education des Adultes, le Réseau International de Recherche Participative a été créé. Les différents courants ont favorisé l'émergence de la recherche-action critique, recherche-action, recherche-intervention, etc. Bien que l'Europe ait aussi joué un rôle pionnier, dans les années 1970, pour créer des liens entre chercheurs et société civile grâce aux boutiques de sciences établies d'abord dans les universités néerlandaises, la recherche participative semble aujourd'hui plus solidement établie au Canada, aux États-Unis, en Inde, et dans plusieurs pays sud-américains et africains. La recherche-action / recherche-action participative / recherche-action collaborative se caractérise par « *un engagement politique et idéologique de transformation sociale de la part du chercheur à l'égard des secteurs subalternes de la société. Le chercheur est considéré* […] *comme un intellectuel qui milite en faveur des intérêts du mouvement populaire. Dans ce contexte, la recherche-action constitue un important espace de participation sociale et une méthode d'action politique*[4]*.* Cette modalité de recherche rend « *l'acteur chercheur et fait du chercheur un acteur qui oriente la recherche vers l'action et qui ramène l'action vers des considérations de recherche. C'est une recherche impliquée, refusant le pari positiviste de l'observation neutre et externe des phénomènes* »[5] Ce type de recherche vise la production de connaissances nouvelles, la résolution d'un problème identifié par les acteurs et le renforcement des capacités de ces acteurs pour une plus grande autonomie. Cette production de connaissances nouvelles, voire d'outils utiles aux

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[4] Anadon, M. et Savoie-Zajq, L. (2007). La recherche participative, multiple regards, Presses de l'Université du QuébecLa recherche participative, multiple regards.

[5] Hernandez, V. (2002). "Chercheur - Décideur." Journal des anthropologues(88-89).

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praticiens permet de transformer la réalité[6]. Les approches de recherche participative sont ainsi un moyen d'impliquer les citoyens dans la recherche scientifique par l'association de l'expertise citoyenne et de l'expertise scientifique. Elles favorisent également un espace de dialogue et d'action entre citoyens et chercheurs[7].

Patient expert

Cette notion remonre à quelques décennies. Elle désigne l'accroissement de la capacité d'agir de la personne malade via le développement de son autonomie, la prise en compte de son avenir et sa participation aux décisions la concernant. L'empowerment est étroitement lié à la notion de rétablissement. L'empowerment communautaire quant à lui trouve ses racines dans la psychologie communautaire, l'éducation pour la santé et la promotion de la santé, la pédagogie de l'opprimé, l'organisation communautaire, le développement rural et communautaire, et le travail social. L'empowerment a été défini comme « *un processus par lequel les personnes, les organisations et les communautés accroissent la maîtrise des questions qui les concernent* » ; *l'empowerment communautaire étant un « processus d'action sociale par lequel les individus, les communautés et les organisations acquièrent la maîtrise de leurs vies en changeant leur environnement social et politique pour accroître l'équité et améliorer la qualité de la vie* »[8].

Pair aidance

La pair aidance repose sur l'entraide entre personnes souffrant ou ayant souffert d'une même maladie, somatique ou psychique. Le partage du vécu de la maladie et du parcours de rétablissement constitue les principes fondamentaux de la pair aidance qui peut prendre plusieurs formes : participation à des groupes de parole au sein d'association d'usagers, rencontre dans des Groupes d'entraide mutuelle (GEM), ou encore l'intégration de pairs aidants bénévoles ou professionnels dans les services de soins[9].

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[6] Faure, G., Gasselin, P., Triomphe, B., et al. (2010). Innover avec les acteurs du monde rural : la recherche-action en partenariat. Paris : Editions Quae.

[7] Storup, B., Millot, G. et Neubauer, C. (2013). La recherche participative comme mode de production de savoirs : un état des lieux des pratiques en France. Paris : Fondation Sciences Citoyennes

[8] Wallerstein, N. (2006). What is the evidence on effectiveness of empowerment to improve health ? = Dans quelle mesure, selon les bases factuelles disponibles, l'autonomisation améliore-t-elle la santé ? OMS 6 Bureau régional de l'Europe.

[9] Site de Psycom

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Anadon, M. et Savoie-Zajq, L. (2007). La recherche participative, multiple regards, Presses de l'Université du Québec.

Cornwall, A. et Jewkes, R. (1995). "What is participatory research?" Social science & medicine **41**(12): 1667-1676.

Faure, G., Gasselin, P., Triomphe, B., et al. (2010). Innover avec les acteurs du monde rural : la recherche-action en partenariat. Paris : Editions Quae.

Hernandez, V. (2002). "Chercheur - Décideur." Journal des anthropologues (88-89).

Michel, P., Brudon, A., Pomey, M. P., et al. (2020). "Approche terminologique de l'engagement des patients : point de vue d'un établissement de santé français." Revue d'Épidémiologie et de Santé Publique **68**(1): 51-56.

OMS (2006). What is the evidence on effectiveness of empowerment to improve health? Copenhague : OMS**:** 37p.

Storup, B., Millot, G. et Neubauer, C. (2013). La recherche participative comme mode de production de savoirs : un état des lieux des pratiques en France. Paris : Fondation Sciences Citoyennes

Études françaises

OUVRAGES

Andrieu, B. (2012). L'autosanté. Vers une médecine réflexive. Paris, Armand Colin
http://www.cairn.info/l-autosante--9782200280512.htm

> Le patient « bon et docile » n'existe plus. Désormais, le sujet contemporain entend devenir agent de sa santé et refuse de se laisser enfermer dans une simple relation soignant-soigné, vécue sur un mode passif, jusque dans la demande de disposer de son corps. Il s'informe, revendique des droits et entend le faire savoir. En France, la loi dite Kouchner lui garantit, depuis 2002, le droit à accéder à son dossier médical et le devoir des médecins de rechercher le consentement aux soins, tandis que les associations de malades alimentent les forums des sites d'information sur leur vécu.

Autes, E. (2020). Administrer la santé mentale : rhétoriques et politiques de l'expérience. Lyon Ecole nationale supérieure.
https://www.academia.edu/43169909/Administrer_la_sant%C3%A9_mentale_rh%C3%A9toriques_et_p olitiques_de_l_exp%C3%A9rience_Administering_Mental_Health_Rhetorics_and_Policies_of_Ex perience

> L'objectif de cette thèse est d'éclairer les évolutions institutionnelles de la santé mentale en France au cours de la décennie 2010. Dans cette conjoncture, « l'expérience » est devenue une catégorie au fondement d'une nouvelle économie morale dans les politiques publiques questionnant l'expérience de la maladie, les conceptions publiques de l'assistance, le rôle des soins en santé mentale, l'agentivité des malades. Quel est le fondement et les conséquences de cette politique de l'expérience qui déclasse l'expérience clinique (niveau le plus bas de la hiérarchie des preuves dans l'Evidence-Based Medicine) et valorise l'expérience collective des

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patients ? Comment une expérience peut-elle se convertir en expertise ? L'analyse porte non seulement sur les réponses de l'administration, des cliniciens comme d'un nouveau genre de patients à cette question, mais aussi sur le travail de thèse en tant que tel. L'étude est en effet ancrée dans un travail de terrain multi-situé, conçu comme une ethnographie d'assemblage, explorant des manifestations locales d'un problème commun, à partir d'une posture d'agent d'administration locale de la santé. Le corpus est composé d'entretiens (n=24), d'observations (n=84) et des notes de terrain, de 2010 à 2019, recueillis dans différents sites en France, au sein de différentes administrations publiques (mairie, agences régionales de santé).

Deutsch, C., Farcy, A., Maillard, I., et al. (2017). De la disqualification à la prise de parole en santé mentale. Recherche sur les conditions d'émergence, de reconnaissance et de prise en compte de la parole des personnes dites handicapées psychiques par les décideurs publics : Synthèse du rapport final. Paris FIRAH, Paris Advocacy France**:**.
http://www.firah.org/centre-ressources/fr/notice/313/de-la-disqualification-a-la-prise-de-parole-en-sante-mentale-recherche-sur-les-conditions-d-emergence-de-reconnaissance-et-de-prise-en-compte-de-la-parole-des-personnes-dites-handicapees-psychiques-par-les-decideurs-publics.html

> La recherche-action initiée par Advocacy France, et soutenue par la CNSA et la FIRAH, se proposait d'associer les personnes volontaires des Groupes d'entraide mutuelle intéressées avec des chercheurs expérimentés dans ce type de démarche, pour explorer les difficultés rencontrées par les personnes dites handicapées psychiques dans leurs relations aux institutions (inclusion sociale, droits, discriminations, accès à la prévention et aux soins..). Les problèmes récurrents de compréhension, d'accessibilité et de prise en compte supposaient, pour dépasser le stade des constats, d'engager une dynamique impliquant les personnes intéressées, tant pour identifier les déterminants sur lesquels il serait possible d'agir que pour engager des dynamiques de changement. La proposition de recherche se fondait sur la possibilité de mobiliser les savoirs d'expérience et le potentiel d'interpellation directe des institutions par des « usagers » de la psychiatrie ou de la santé mentale qualifiés ici de « chercheurs-acteurs ». Au travers d'un travail en focus group ont été forgés les différents outils d'investigation qui seront utilisés dans l'enquête auprès des acteurs et institutions concernés. Ce document constitue une synthèse des résultats de cette recherche action.

Fédération Addiction, F. (2021). Participation des usagers : de l'implication à la coopération, Paris : Fédération Addiction
https://www.federationaddiction.fr/parution-du-guide-participation-des-usagers-de-limplication-a-la-cooperation/

> Le guide Participation des usagers : de l'implication à la coopération, de la collection Repère(s, est le fruit de 3 années de démarche participative au sein du réseau de la Fédération Addiction et de ses partenaires. Son objectif est de dresser un état des lieux des pratiques d'implication des usagers dans leur parcours de soins, dans leur structure d'accueil et d'accompagnement, auprès de leurs pairs et dans la société. Ce travail rend compte de la diversité des pratiques permettant de (re-)donner aux usagers leur pouvoir d'agir et de co-construire un parcours de soins qui convienne à leurs besoins et qui permette d'améliorer leur qualité de vie. Soutenu par la Direction Générale de la Santé, ce projet a été conduit en lien avec le Conseil d'Administration de la Fédération Addiction. Il a été élaboré par un groupe de travail paritaire – composé

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d'autant de professionnels des soins que d'usagers – et partenarial – intégrant des associations d'entraide et d'auto-support.

Franck, N. et Celland, C. (2020). Pair-aidance en santé mentale : une entraide personnalisée. Paris : Elsevier

Gagnon, J. (2012). Empowerment. Les concepts en sciences infirmières. Toulouse, Association de recherche en soins infirmiers (ARSI)**:** 172-175.
https://www.cairn.info/concepts-en-sciences-infirmieres-2eme-edition--9782953331134-page-172.htm

> Les concepts constituent la base de la discipline infirmière. Les appréhender dans une visée scientifique est fondamental pour l'exercice clinique et l'enseignement de la discipline. Cet ouvrage met à la disposition des infirmiers et infirmières, et autres personnes intéressées, un ensemble de concepts, issu des sciences humaines, utilisés dans la pratique courante des soins. La première partie de l'ouvrage est constituée par une approche épistémologique des concepts : définition, construction, propriétés, transférabilité, évolution, et par une approche pédagogique : enseignement, apprentissage, maîtrise. Dans la deuxième partie une centaine de concepts de soins sont développés selon le modèle d'analyse des concepts de Wilson : présentation, origine, définition, attributs, concepts voisins, utilisation du concept dans la pratique professionnelle. Les 100 concepts sont répertoriés par ordre alphabétique. Certains sont très connus : nursing, besoins, clinique, autonomie, éthique, anxiété, éducation thérapeutique, culture, interdisciplinarité... D'autres un peu moins : résilience, coping, observance, interaction, espoir, motivation, counselling, empowerment... Les auteurs qui ont rédigé les concepts sont des infirmiers et/ou des universitaires qui au cours de leur cursus professionnel ont eu l'occasion d'approfondir le concept.

Goulinet, G. (2013). Rôle socio culturel des communautés virtuelles de patients dans le suivi des maladies chroniques : vers un nouveau modèle d'éducation thérapeutique ? Bordeaux Université de Bordzaux 3, Université Bordeaux 3. UFR Sciences des Territoires et de la Communication. Institut des Sciences de l'Information et de la communication. Bordeaux. FRA. Mémoire de recherche Master 2 ; Ingénierie de la recherche en sciences de l'information et de la communication - spécialité Communication Réseaux et Société**:** 121.
https://www.academia.edu/10762058/R%C3%B4le_socio_culturel_des_communaut%C3%A9s_virtuelles_de_patients_dans_le_suivi_des_maladies_chroniques_vers_un_nouveau_mod%C3%A8le_d%C3%A9ducation_th%C3%A9rapeutique_?auto=download

> En même temps que ce sont modifiées les relations médecin-patient avec les évolutions socio-culturelles, passant d'un modèle biomédical à un modèle biopsychosocial, la reconnaissance du patient, dans sa globalité, lui a permis d'acquérir un « pouvoir d'agir ». Par ailleurs, l'émergence d'internet, a formalisé la mutation de ce processus communicationnel en lui permettant un accès direct à l'information, au savoir médical et à l'apprentissage de sa santé. La forte proportion des maladies chroniques a surenchéri ce phénomène en engageant les pouvoirs publics a développé une éducation thérapeutique afin que ce dernier puisse développer des compétences en auto-soins et en adaptation, sous couvert de l'enseignement des professionnels. Or, le pouvoir donné aux patients d'expression, d'échanges, de partage d'expériences et de connaissances a forgé une culture communautaire basé sur l'entraide et l'apprentissage social autour d'intérêt et d'engagement commun. Avec le numérique, l'arrivée de sites web dédiés aux communautés virtuelles de patients interrogent sur la place

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qu'occupent maintenant ces dispositifs dans la relation éducative, qui semblent favoriser l'émergence d'usages et des pratiques en devenir.

Greacen, T. et Jouet, E. (2019). Pour des usagers de la psychiatrie acteurs de leur propre vie : rétablissement, inclusion sociale, empowerment, Toulouse : Erès

> Par le rétablissement, l'inclusion sociale et l'empowerment, une personne vivant avec un trouble psychique devient actrice de sa propre vie, citoyenne à part entière, experte de son expérience. La notion de rétablissement rappelle que, même pour des pathologies lourdes comme la schizophrénie, les psychoses, la majorité des personnes peuvent se rétablir et mener une vie comme tout un chacun. L'inclusion sociale ajoute l'idée que, si la moitié du travail vers le rétablissement est l'affaire de l'usager, l'autre moitié du travail est à faire par la société elle-même. De même qu'on aménage la ville pour que la personne en fauteuil roulant puisse s'inclure dans la société, on doit aménager les esprits et l'organisation de la vie de tous les jours pour supprimer tout mécanisme d'exclusion sociale, toute stigmatisation, toute discrimination contre la personne handicapée psychique. Enfin, l'empowerment consiste à mettre à la disposition de la personne les moyens pour acquérir les savoirs, savoir-faire et pouvoirs nécessaires – notamment par l'accès à la formation tout au long de la vie – pour apprendre à vivre avec sa maladie et jouer un vrai rôle dans la société.

Gross, O., Lombrail, P. et Gagnayre, R. (2017). L'engagement des patients au service du système de santé, Paris : Doin

> Patients-partenaires, patients-experts, patients-intervenants dans l'éducation thérapeutique de leurs pairs, patients-enseignants... Le rôle grandissant des patients dans le système de santé questionne, tant sur les fondements de ce phénomène que sur les modalités pratiques de leur engagement. Le slogan associatif "Rien sur nous, sans nous" inscrit ce mouvement dans une revendication morale. C'est aussi lui faire justice que de présenter son intérêt pour la qualité du système de santé. L'engagement des patients dans le système de soins sert de levier supplémentaire à la qualité des soins, à partir de différents constats : les actions verticales ne fonctionnent pas, l'expérience des soins des patients peut servir à améliorer les parcours de soins, leur parole a une légitimité particulière auprès des autres malades. Enfin, leurs savoirs situés et leur perspective singulière permettent de concevoir des actions de santé innovantes, ou plus pertinentes au regard des attentes des malades. Ainsi, des patients engagés participent aux actions de prévention en santé, aux soins de leurs pairs, aux recherches, à la formation des médecins. Dans certains champs, leur participation devient un critère de qualité des actions de santé. Cet ouvrage décrit le processus sociohistorique dans lequel s'inscrit le mouvement de l'engagement des patients. Il dresse un panorama des expériences étrangères et françaises et un état des recherches. Il contient de nombreuses références bibliographiques utiles au milieu scientifique et estudiantin, et apporte des éléments de compréhension et des conseils pratiques de mise en oeuvre aux acteurs de terrain.

Haute Autorité de Santé (2013). Patient et professionnels de santé : décider ensemble. Concept, aides destinées aux patients et impact de la « décision médicale partagée ». Paris : HAS**:** 76p.
https://www.has-sante.fr/portail/jcms/c_1671523/fr/patient-et-professionnels-de-sante-decider-ensemble

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La décision médicale partagée correspond à l'un des modèles de décision médicale qui décrit deux étapes clés de la relation entre un professionnel de santé et un patient que sont l'échange d'informations et la délibération en vue d'une prise de décision acceptée d'un commun accord concernant la santé individuelle d'un patient. Des aides à la décision destinées aux patients peuvent être proposées et ont fait preuve de leur efficacité pour augmenter la participation du patient qui le souhaite aux décisions qui concernent sa santé. Associées à d'autres mesures organisationnelles, elles peuvent améliorer la qualité et la sécurité des soins. Le contenu de ces aides vise à : rendre explicite la décision à prendre et les raisons qui nécessitent qu'elle soit prise ; guider le patient afin qu'il hiérarchise les options disponibles selon ses préférences en fonction des bénéfices et des risques qui ont de la valeur, de l'importance pour lui, et de son degré de certitude vis-à-vis de ses préférences ; expliciter les étapes du processus décisionnel et de communication avec les autres personnes impliquées dans la décision (médecin, famille, proches).

Jouet, E., Flora, L. et LasVerghnas, O. (2020). Construction et reconnaissance des savoirs expérientiels des patients : Note de synthèse, HAL
https://hal.archives-ouvertes.fr/hal-00645113/document

Les schémas de production et de reconnaissance des savoirs dans le domaine de la santé se modifient profondément : pour les pathologies chroniques notamment, les expertises propres aux malades émergent comme sources de savoirs : les stratégies classiques d'éducation thérapeutique, proposées par les soignants pour améliorer l'observance des traitements, se doublent de nouveaux courants issus des communautés de malades qui rattachent les maladies à des formations expérientielles, voire à des épisodes autodidactes. Après avoir été resituée historiquement comme constitutive de l'idée de démocratie sanitaire, cette reconnaissance des savoirs expérientiels des patients – en marche dans de multiples lieux – fait ici l'objet d'une revue de littérature qui en regarde les enjeux épistémologiques, thérapeutiques et de pouvoir.

Jouet, E. et Greacen, T. (2012). Pour des usagers de la psychiatrie acteurs de leur propre vie. Rétablissement, inclusion sociale, empowerment. Toulouse, ERES
http://www.cairn.info/pour-des-usagers-de-la-psychiatrie-acteurs-de-leur--9782749216089.htm

Les trois notions, rétablissement, inclusion sociale et empowerment, créent un nouveau paradigme qui situe l'usager de la psychiatrie comme moteur de sa propre vie, au sein d'une collectivité dans laquelle il est citoyen à part entière et où les services de santé mentale se donnent les moyens de soutenir son autonomie plutôt que de perpétuer son rôle traditionnel de « patient ». Déclinées dans cet ouvrage à travers de multiples expériences concrètes dans divers pays, elles sont au centre d'un débat né du constat de l'échec de nos sociétés occidentales contemporaines à pleinement réintégrer les personnes vivant avec un trouble psychique. La notion de rétablissement rappelle que, même pour des pathologies lourdes comme la schizophrénie, les psychoses, la majorité des patients se rétablissent et mènent leur vie comme tout un chacun. L'inclusion sociale ajoute l'idée que, si la moitié du travail vers le rétablissement est l'affaire de l'usager, l'autre moitié du travail est à faire par la société elle-même. De même qu'on aménage la ville pour que la personne en fauteuil roulant puisse s'inclure dans la société, on doit aménager les esprits et l'organisation de la vie de tous les jours pour supprimer tout mécanisme d'exclusion soc ale, toute stigmatisation, toute discrimination contre la personne handicapée psychique. Enfin l'empowerment consiste à mettre à la disposition de la personne les moyens pour acquérir les savoirs et pouvoirs nécessaires - notamment par l'accès à la

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formation tout au long de la vie - pour apprendre à vivre avec sa maladie et jouer un vrai rôle dans la société.

Jouet, E., et al. (2014). Nouvelles coopérations réflexives en santé : de l'expérience des malades et des professionnels aux partenariats de soins, de formation et de recherche. Editions des Archives contemporaines

 Les champs de la recherche, de la pédagogie et de la thérapeutique médicales sont aujourd'hui bouleversés par la volonté de prendre au mieux en compte la réflexivité de tous les protagonistes. Associant chercheurs, malades et professionnels de la santé, cet ouvrage analyse des partenariats inédits de soins, de formation et de recherche qui en découlent en Europe, au Québec et au Brésil. Il fournit un point d étape des nouvelles mobilisations de la réflexivité des malades et des soignants et de leurs effets, observant tant le déploiement de figures formalisées de représentants des usagers, patients experts, patients formateurs et patients co-chercheurs, que celui des premières promotions de docteurs en sciences infirmières. Deux conclusions s'en dégagent : d'une part la progression de la prise en compte des savoirs des malades métamorphose les notions d'éducation thérapeutique et de démocratie sanitaire et questionne la formation des médecins et soignants ; d'autre part la construction d'enseignements universitaires des sciences infirmières oblige à la formalisation d'un modèle encore implicite de formation par la recherche. Plus généralement, dès lors que soigner ou maintenir en bonne santé est pensé comme un ensemble de coopérations entre personnes capables de réfléchir et disposant de leur libre arbitre, la valorisation de la réflexivité de tous devient essentielle.

Jouet, E. (2014). La recherche en santé et les patients : de l'utilisation des corps à la contribution active. In : Nouvelles coopérations réflexives en santé : de l'expérience des malades et des professionnels aux partenariats de soins, de formation et de recherche. Editions des Archives contemporaines.

Saïas, T. (2011). Introduction à la psychologie communautaire. Paris, Dunod
http://www.cairn.info/introduction-a-la-psychologie-communautaire--9782100566907.htm

La psychologie communautaire est une discipline psychologique nouvelle, qui s'est récemment formalisée en France, au carrefour de la psychologie sociale et de la psychologie de la santé. L'objectif de cet ouvrage est de rassembler les différentes pratiques des psychologues pour mettre en évidence les éléments centraux permettant aux professionnels de passer d'une logique centrée sur l'individu à une logique collective et de territoire. La psychologie communautaire est une discipline psychologique nouvelle, qui s'est récemment formalisée en France, au carrefour de la psychologie sociale et de la psychologie de la santé. L'approche communautaire de la psychologie permet d'agir sur les déterminants politiques et sociaux de la santé et du développement des individus et des collectivités. L'objectif de cet ouvrage est de rassembler les différentes pratiques des psychologues acteurs du développement social, pour mettre en évidence les éléments centraux permettant aux professionnels de passer d'une logique centrée sur l'individu à une logique collective et de territoire.

Velpry, L. d., Vidal-Naquet, P. A. d. et Eyraud, B. d. (2018). Contrainte et consentement en santé mentale : forcer, influencer, coopérer, Rennes : Presses Universitaires de Rennes

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La démocratisation des pratiques d'aide et de soin est au coeur des politiques sanitaires, sociales et médico-sociales depuis la fin du XX° siècle. Rechercher le consentement, éviter la contrainte en constituent les deux injonctions dominantes. En effet, les règles qui encadrent les pratiques de prise en charge visent à réduire la dimension contraignante de l'aide, à garantir le droit à l'information et la participation des personnes, ainsi que leur protection. En situation, les professionnels sont souvent confrontés à des conflits normatifs qui deviennent indécidables quand les personnes souffrent d'une altération de leurs capacités mentales. Comment faire alors, lorsque, à défaut de pouvoir "protéger sans contraindre", il faut envisager de "contraindre pour protéger" ?

ARTICLES

(2017). "Appel pour le développement des recherches participatives en croisement des savoirs." Vie sociale **20**(4): 53-57.
https://www.cairn.info/revue-vie-sociale-2017-4-page-53.htm

> Ce numéro porte sur les Pairs, leur participation à la recherche, les effets de cette participation, et les différentes expertises en débat (sciences citoyennes, ATD Quart-Monde, expertise des pairs-aidants).

(2017). "Le patient dans le système de santé." Revue française des affaires sociales(1): 248.

> Ce dossier sur « Le patient et le système de santé » est structuré autour de trois axes de réflexion : la prise en compte du patient par les institutions et les professionnels de santé ; l'évolution des compétences ; la démocratie sanitaire et la place des usagers dans le fonctionnement du système de santé. Ces développements sont suivis par de comparaisons internationales ainsi que d'un focus sur la politique britannique d'implication des patients et du public. Puis, la place des patients dans les parcours de prise en charge du cancer est évoquée. Enfin, une revue de littérature développe le thème de l'accès aux soins .

Bizet, C., Defromont, L. et Labey, M. (2020). "Des « experts d'expériences » pour former des professionnels de santé mentale." Le Journal des psychologues **377**(5): 56-61.
https://www.cairn.info/revue-le-journal-des-psychologues-2020-5-page-56.htm

> Depuis les années 1980, un axe fondamental du projet du pôle de santé mentale des villes de Mons-en-Barœul, Hellemmes, Lesquin, Lezennes, Ronchin et Faches-Thumesnil (pôle 59G21) est la lutte contre la stigmatisation des personnes souffrant d'un trouble de santé mentale. Ce pôle, reconnaissant l'importance du rôle des savoirs expérientiels dans le parcours de rétablissement des usagers, fait évoluer son organisation. Il s'attache à favoriser « l'empowerment » des usagers et la participation d'experts d'expériences au sein des services (Labey, 2017). L'« empowerment », parfois appelé « pouvoir d'agir », « capacité d'agir », « empouvoirement » ou encore « en-capacitation » chez les francophones canadiens (Daumerie, 2011), pourrait ainsi se traduire par « reprise du pouvoir » des usagers. Une des actions impulsées par le pôle depuis 2016 est la formation des professionnels par des experts d'expériences. Ainsi, des personnes directement concernées par des problèmes de santé mentale, avancées dans leur parcours de rétablissement, viennent partager leurs expériences, dire aux professionnels ce qu'est le rétablissement selon eux, et les renseignent sur les attitudes qui peuvent ou non aider les «

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patients ». Plus loin dans cet article, nous présenterons cette action plus en détail et exposerons les grands principes et conseils tirés de l'enseignement des experts qui sont intervenus dans ce pôle.

Bonnet, C. (2020). "Professionnalisation des pairs aidants : une impasse ?" Pratiques en santé mentale **66e année**(3): 26-39.
https://www.cairn.info/revue-pratique-en-sante-mentale-2020-3-page-26.htm

Clément Bonnet, président de Santé Mentale France pour la région Île France n'hésite pas à apparaître à contre courant pour le jugement éventuel de certains partisans de la pair-aidance. Sa longue expérience des dispositifs psychiatriques lui fait envisager la pair-aidance professionnelle comme une possible impasse. Autant examiner les arguments dont il paraît difficile de réfuter la solidité, énoncés selon trois ordres.Tout d'abord, il relève un contraste flagrant entre le désarroi actuel dans les établissements de santé mentale et l'optimisme d'une insertion professionnelle de pairs-aidants figurant plus comme un mirage qu'un véritable remède.Ensuite, il analyse le flou des contours de ce nouveau métier : l'imprécision face aux statuts professionnels définis, l'indétermination des compétences des pairs-aidants et leur absence de véritable spécificité, non réductible au seul savoir expérientiel.Enfin, il pointe les risques et dangers, en particulier celui d'un inconfort de difficilement pouvoir trouver leur place dans un collectif soignant dont la cohérence constitue une exigence impérative.Néanmoins, à nombre de reprises, l'auteur nuance son propos. Il salue la pair-aidance dans les GEM, se montre favorable à l'animation d'ateliers avec des pairs-aidants bénévoles et, même, rémunérés sous réserve que leurs interventions se fassent par l'intermédiaire de plateformes associatives indépendantes de la hiérarchie des établissements de santé mentale.

Bossé, P. L., Carrier, S. et Morin, P. (2018). "Le projet Baromètre, un outil numérique et collaboratif. Pertinence et utilité dans le champ de la santé mentale." L'information psychiatrique **94**(10): 802-808.
https://www.cairn.info/revue-l-information-psychiatrique-2018-10-page-802.htm

RésuméDepuis plusieurs années, notre équipe (Université de Sherbrooke, Québec) poursuit diverses recherches sur la personnalisation des soins et des services. Cette approche s'appuie sur le triptyque suivant : la valorisation des savoirs d'expérience, l'évaluation de la différence produite par les soins et services dans la vie des gens et la coproduction de ces derniers par les professionnels et les usagers. De fil en aiguille, ces recherches ont inspiré la conception et le développement participatif d'une plateforme numérique et collaborative : le projet Baromètre. Cet article explicitera la démarche de conception et de validation scientifique réalisée à ce jour. Il présentera également l'utilité et la pertinence de cet outil : résultats de recherche circonscrits à partir de 72 histoires d'utilisation.

Boudier, F., Bensebaa, F. et Jablanczy, A. (2012). "L'émergence du patient-expert : une perturbation innovante." Innovations **39**(3): 13-25.
https://www.cairn.info/revue-innovations-2012-3-page-13.htm

RésuméCette recherche examine la transformation de la relation médecin-patient, suite à l'émergence de patients-experts. L'exploration de cette innovation comportementale permet de proposer deux résultats majeurs : la définition du patient-expert sur la base de l'asymétrie de connaissance (et non plus d'information) ; la formalisation et la conceptualisation de la nouvelle relation qui se développe entre médecins et patients-experts. Plusieurs perspectives de

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recherche sont dès lors envisageables : l'évolution de l'innovation comportementale vers l'innovation organisationnelle ; l'effet des nouveaux partenariats patients/médecins sur l'organisation des systèmes de santé ; le mode opératoire possible pour faire dialoguer les acteurs à l'aune de la nouvelle interaction ; la méthodologie susceptible d'être employée pour développer des travaux empiriques, eu égard à la rareté des travaux existants.Codes JEL : D83, I18, O31

Brun, P. (2017). "Le croisement des savoirs dans les recherches participatives. Questions épistémologiques." Vie sociale **20**(4): 45-52.
https://www.cairn.info/revue-vie-sociale-2017-4-page-45.htm

> Le mouvement ATD Quart Monde et le Conservatoire national des arts et métiers (Cnam) ont organisé en 2015-2016 un séminaire épistémologique autour des recherches participatives en croisement des savoirs avec des représentants de milieux de pauvreté et des professionnels. Le but était d'établir les plus-values de recherches académiques menées en croisement des savoirs avec ces acteurs et de préparer un appel aux chercheurs en faveur de cette démarche. Trois problématiques ont structuré nos réflexions : la nature des savoirs expérientiels et les questions posées par la mise en dialogue de ces savoirs avec les savoirs académiques ; les conditions du processus relationnel mis en œuvre dans le croisement ; enfin, les critères de validation compte tenu des finalités différentes des participants et les modalités d'une co-validation. Des consensus ont été actés, les bénéfices attendus pour chacun des co-chercheurs identifiés et un certain nombre de débats menés ouvrant sur un travail d'approfondissement de cette forme de recherche.

Cases, A.-S. (2017). "L'e-santé : l'empowerment du patient connecté." Journal de gestion et d'économie médicales **35**(4): 137-158.
https://www.cairn.info/revue-journal-de-gestion-et-d-economie-medicales-2017-4-page-137.htm

> L'objectif de cette recherche est de mieux comprendre les apports du numérique dans la sphère médicale avec une approche centrée autour du patient. Aujourd'hui, Internet a transformé la façon dont le patient a accès à l'information santé, ce patient dit « connecté » est de plus en plus informé et devient un acteur de sa santé. Conjointement, certains dispositifs numériques de santé contribuent également à impliquer les patients dans le processus de soin. Aussi, le concept d'empowerment du patient prend tout son sens avec l'arrivée des technologies numériques. Une revue de la littérature relative au concept d'empowerment du client puis du patient a été menée et complétée par deux études qualitatives complémentaires. Il s'agit d'identifier les sources de pouvoir associées au numérique et à l'empowerment du patient ainsi que les bénéfices et les risques de ce gain de pouvoir ressenti par ces derniers.

Chambon, N., Traverso, V., Zeroug-Vial, H., et al. (2020). "Pair-aidance, interprétariat et médiations." Rhizome(75-76): 204.
http://www.ch-le-vinatier.fr/documents/Publications/RHIZOME_Orspere-
        Samdarra/Cahiers_Rhizome_75-76.pdf

> Une transformation plus ou moins tranquille traverse aujourd'hui les structures sanitaires et sociales. D'un côté, les métiers représentés au sein des établissements sanitaires, sociaux ou médico-sociaux se retrouvent « fragilisés ». Des psychologues s'interrogent par exemple sur la pertinence de l'évolution de la psychiatrie publique – diffusion du concept de « rétablissement

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», développement de la réhabilitation psychosociale –, et sur leur place dans ces évolutions. Des soignants et des intervenants sociaux alertent également sur le manque de moyens pour mener à bien leur mission dans des structures en « crise ». D'un autre côté, se développent des métiers plus ou moins nouveaux (médiateur de santé-pair, interprète…) dont le nombre augmente chaque année. Ce développement est quantitatif, mais surtout qualitatif, puisque les formations qui sont proposées impliquent une « montée en compétences » de ces intervenants.

Chevallier, F., Duhot, D., Ruelle, Y., et al. (2020). "Plaidoyer pour l'intégration des patients formateurs dans l'enseignement des futurs médecins généralistes à partir de l'expérience de l'université Sorbonne Paris Nord et de la littérature internationale." Revue française des affaires sociales(1): 281-293. https://www.cairn.info/revue-francaise-des-affaires-sociales-2020-1-page-281.htm

> Dans un contexte de virage ambulatoire, d'augmentation des pathologies chroniques et de nécessité de rendre plus effectifs les parcours de soins encore trop souvent opaques pour les patients, il est urgent de repenser la place et le rôle des différents acteurs du système de soins primaires – en particulier, l'intégration du patient dans la formation spécialisée, mais aussi la formation initiale des médecins généralistes qui est susceptible d'améliorer leurs compétences humaines et cliniques et de changer en conséquence les représentations des étudiants sur leur exercice futur. Certains programmes intègrent des patients dans l'enseignement depuis plusieurs années. Leur impact dépasse la prise en compte de la perspective patient et touche toutes les compétences des futurs médecins. Leur implication peut et doit se faire à tous les niveaux, de l'animation des cours à la gouvernance des différentes instances. Cela doit ouvrir la voie à un partenariat plus harmonieux dans la gestion de soins primaires, voire au-delà. L'université peut avoir un rôle à jouer via la recherche académique tout en adossant cette mission à une nouvelle forme de responsabilité sociale, en permettant l'émergence d'un système non seulement basé sur les preuves, mais également sur des valeurs communes avec les usagers.

Cloutier, G., Maugiron, (2016). "La pair aidance en santé mentale : l'expérience québécoise et française." L'information psychiatrique **92**(9): 760. https://www.cairn.info/revue-l-information-psychiatrique-2016-9-p-755.htm

> Dans cet article, nous aborderons la pratique innovante de l'intégration de pairs aidants certifiés ou médiateurs de santé pair au sein des secteurs de la psychiatrie ou du médico-social au Québec et en France.

Conus, P., Baki, A. A., Krebs, M. O., et al. (2019). "Mieux diffuser le savoir et l'expérience relative à l'intervention précoce dans les troubles psychiatriques : création d'une branche francophone de l'IEPA." L'information psychiatrique **95**(3): 155-158. https://www.cairn.info/revue-l-information-psychiatrique-2019-3-page-155.htm

> RésuméBien que les concepts d'intervention précoce dans la psychose et les autres troubles psychiatriques soient bien établis et qu'ils se soient implantés dans plusieurs pays à travers le monde, les pays francophones sont en retard à l'égard de ces développements, à l'exception du Québec. De manière à promouvoir l'information relative à ce domaine, à la rendre accessible aux personnes ne maîtrisant pas l'anglais et à fédérer les forces de francophonie motivées à développer ce genre d'intervention, l'initiative a été prise de lancer une branche francophone de l'association IEPA (Early Intervention in Mental Health). Les objectifs sont d'organiser une

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conférence annuelle en français, de favoriser les échanges de compétence et les outils développés en français et de renforcer les collaborations en facilitant l'organisation de stages en immersion ainsi que de formations théoriques.

Cosson, J. F., Brun-Jacob, A., Marchand, J., et al. (2019). "La recherche participative CiTIQUE." Santé Publique **S1**(HS): 89-90.
https://www.cairn.info/revue-sante-publique-2019-HS-page-89.htm

Daumerie, N. (2011). "L'empowerment en santé mentale : recommandations, définitions, indicateurs et exemples de bonnes pratiques." La Santé de l'homme(413): 8-10.
http://www.inpes.sante.fr/SLH/pdf/sante-homme-413.pdf

> Psychologue, chargé de mission au Centre collaborateur de l'OMS pour la recherche et la formation en santé mentale, Nicolas Daumerie définit la notion d'empowerment et présente le programme commun de l'OMS et de la Commission européenne pour l'empowerment en santé mentale. Dans ce cadre, une centaine de « bonnes pratiques » a été recensée en Europe. Toutes ont le même fil conducteur qu'un expert britannique résume ainsi : « Nous ne pouvons pas être "émancipés"par autrui, nous ne pouvons nous "émanciper" que par nous-mêmes. »

de la Chenelière, M. (2018). "De patient à chercheur : parcours d'empowerment autour de la transidentité." L'information psychiatrique **94**(10): 817-823.
https://www.cairn.info/revue-l-information-psychiatrique-2018-10-page-817.htm

> RésuméJe suis une femme trans de 67 ans, j'occupe ma retraite en soutenant des personnes en transition en tant que thérapeute certifiée et je participe à des travaux de recherche. Cet article est pour moi une gageure. Comment parler d'un sujet concernant la minorité à laquelle j'appartiens, pourtant très investie par les « spécialistes » de la transidentité ? Je choisis dès à présent mon camp et je vais écrire mon cheminement qui est celui d'une personne trans qui a évolué dans un paysage psychiatrique lui-même en évolution au sujet de la transidentité. Ma participation à l'étude terrain sur « le diagnostic d'incongruence de genre » menée dans le cadre de la révision de CIM 10 en CIM 11 par le CCOMS (Centre collaborateur de l'OMS pour la recherche et la formation en santé mentale en France), me permet de poser le regard d'une « citoyenne-patiente » sur le chemin parcouru et celui qui reste à faire.

Desmons, P. (2018). "Citoyenneté OU Empowerment : « encore un effort » ?" L'information psychiatrique **94**(10): 797-801.
https://www.cairn.info/revue-l-information-psychiatrique-2018-10-page-797.htm

> RésuméPourquoi dire « empowerment » quand on parle français ? Difficile à traduire en un seul mot, la résistance de cet « intraduisible » est analysée ici comme l'indice, voire le symptôme, à la fois d'un enjeu de philosophie politique (une certaine difficulté à penser la domination ?), et d'un enjeu épistémologique (un retour du refoulé du discours savant institué ?).Cette analyse permet peut-être alors d'associer deux mouvements en cours en santé mentale et d'en rendre une certaine lisibilité : l'empowerment des « usagers », au-delà de la « citoyenneté », mais aussi l'émergence du savoir expérientiel, au-delà du savoir « savant ».

Demoustier, S. et Priou, J. (2013). "Les lois de 2002 et la participation des usagers dix ans après." Contraste **37**(1): 73-92.

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https://www.cairn.info/revue-contraste-2013-1-page-73.htm

>Dix ans après la loi qui définit un cadre aux relations entre les professionnels et les « usagers » placés au centre du dispositif, ce numéro dresse un bilan de ses effets au niveau de l'action médico-sociale précoce. Ainsi des parents de jeunes enfants, directement concernés, mais aussi des parents d'enfants qui ont grandi apportent leur témoignage : se sentent-ils considérés comme partenaires ou comme patients ? Comment ont-ils vécu ce qui leur a été dit par les professionnels, au moment de l'annonce, à chaque étape des changements d'orientation ? Ont-ils le sentiment que leur souffrance et celle de leur famille a été prise en considération ? Comment utilisent-ils les moyens d'information : associations de parents, réseaux sociaux et Internet ? De leur côté, les professionnels confrontent leur expérience des relations avec les parents : comment partagent-ils le secret professionnel ? Associent-ils les parents aux réunions de synthèse ? Les projets individualisés sont-ils construits, ou font-ils l'objet d'un contrat ou d'une prestation de service ? Comment les équipes mettent-elles en tension la réglementation et la clinique ? Ces questions sensibles peuvent être sources de malentendus. Elles restent d'une brûlante actualité tant pour les parents que pour les équipes.

Deutsch, C. (2017). "Des usagers en santé mentale chercheurs en sciences sociales." Vie sociale **20**(4): 197-213.

Durand, M. (2014). "L'empowerment : au-delà du terme, vers une démarche particulière." Empan **94**(2): 144-148.
https://www.cairn.info/revue-empan-2014-2-page-144.htm

>Au-delà de sa caractéristique d'être intraduisible, l'empowerment est une notion anglo-saxonne adaptable en France, notamment dans le domaine de l'action sociale. En mettant les acteurs et les usagers au cœur de leurs responsabilités, cette notion se transforme en un processus proactif. L'article est basé sur des exemples d'organismes à but non lucratif américains. Il montre en quoi les choix de financement, la participation active des membres, la gestion ciblée des bénévoles et la pratique de l'évaluation permettent, entre autres, d'engendrer une telle démarche.

Durand, B. (2020). "Les origines de la pair-aidance." Pratiques en santé mentale **66e année**(3): 6-13.
https://www.cairn.info/revue-pratique-en-sante-mentale-2020-3-page-6.htm

>La large connaissance de Bernard Durand, président d'honneur de Santé Mentale France, permet une vision quasi-exhaustive sur l'histoire de la notion. Présentée généralement, elle intéresse d'abord l'addiction : l'alcool puis autres drogues. Deux autres moments significatifs ont jalonné cette histoire : la lutte contre le sida et la pair émulation dans le champ du handicap porté par le slogan « rien à notre sujet sans nous ».Plus spécifiquement pour la santé mentale, parmi les nombreux précurseurs, retenons le Clubhouse dès les années 1940, le club des Peupliers, fondé en 1960 par Philippe Paumelle, médecin-directeur du 13ème arrondissement de Paris et les « survivants de la psychiatrie » aux USA à la fin des années 1970. L'auteur ajoute une mention sur les pairs aidants « à leur insu » : les adhérents des GEM, organisés par la FNAPSY dès 1992, puis officialisés et largement implantés par la loi de 2005.Il conclut avec la professionnalisation des médiateurs de santé pairs : leur rôle fondamental pour lutter contre la discrimination, contribuer au pouvoir d'agir et faire vivre la démocratie.

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Ellafi, R. (2019). "ComPaRe : donner la parole aux patients pour accélerer la recherche médicale." <u>Un Autre Regard</u>(2): 10-11.

> Les patients en psychiatrie, au même titre que les autres patients, pourront s'associer au nouveau dispositif ComPaRe - la Communauté des patients pour la recherche médicale. En effet, ce projet de recherche innovant a pour ambition d'accélérer la recherche sur l'ensemble des maladies chroniques, y compris les maladies psychiatriques trop souvent délaissées.

Ferroud, G. (2020). "Dispositif innovant et pair-aidance : ENTRELIEN, le maillon manquant…." <u>Pratiques en santé mentale</u> **66e année**(3): 58-63.
https://www.cairn.info/revue-pratique-en-sante-mentale-2020-3-page-58.htm

> L'auteur nous fait part d'une expérience tout à fait originale : la création d'une structure animée par des médiateurs de santé pairs qui se situe dans un espace vide entre le GEM (social) et le lieu de soin (sanitaire). Sa compétence : la connaissance de la pathologie bipolaire et des méthodes personnellement éprouvées par les pairs-aidants pour la canaliser, éviter ses excès et pouvoir vivre avec au jour le jour dans une vie aussi satisfaisante que possible. Elle fait le lien entre tous les acteurs qui gravitent autour de la personne malade afin qu'elle-même puisse organiser le modèle de vie, apaisée et évitant les excès dus à la maladie, qu'elle aura choisi.

Flora, L., et al. (2016). "Chapitre 3. L'application d'un modèle intégré de partenariat-patient dans la formation des professionnels de la santé : vers un nouveau paradigme humaniste et éthique de co-construction des savoirs en santé." <u>Journal International de Bioéthique</u> **27**(1): 242.
http://www.cairn.info/revue-journal-international-de-bioethique-2016-1-page-59.htm

> Cet article présente le « Modèle de Montréal », qui offre au patient, s'il le souhaite, de devenir patient partenaire pour l'ensemble des décisions qui le concernent. Nous assistons actuellement à des transformations majeures de nos sociétés occidentales. Les maladies chroniques touchent une proportion grandissante de la population, induisant une transition de la prépondérance de soins aigus à une prépondérance de soins chroniques. D'autres facteurs sociétaux tels que le consumérisme, l'individualisme, la démocratisation de l'information médicale (accélérée par l'avènement d'Internet) et la précarisation d'une partie grandissante des citoyens influencent cette évolution. Dans ce contexte, où la nature et l'envergure des besoins des patients et de leurs proches se modifient comme leurs attentes vis-à-vis des systèmes de santé, une des voies prometteuses pour répondre à ces enjeux réside dans une participation accrue des patients dans leurs propres soins. Depuis 2010, un nouveau modèle relationnel, basé sur le partenariat de soins entre patients et professionnels de la santé, a été développé à partir de la faculté de Médecine de l'Université de Montréal. Ce modèle s'appuie sur la reconnaissance des savoirs expérientiels du patient en complémentarité des savoirs scientifiques des professionnels de la santé. Il s'inscrit dans un continuum d'engagement et de participation des patients qui peut s'appliquer dans l'ensemble des milieux. Qu'il s'agisse de relations singulières ou collectives en interdisciplinarité, ce modèle est actuellement au Québec en cours d'implantation tant dans la formation des professionnels de la santé en milieux de soins, que dans l'enseignement et dans la recherche.

Foucart, J. et Marynowicz-Hetka, E. (2018). "Éditorial. La recherche participative : un travail de l'entre-deux." <u>Pensée plurielle</u> **48**(2): 7-10.
https://www.cairn.info/revue-pensee-plurielle-2018-2-page-7.htm

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Foucart, J. (2011). "Réseaux fluides et pratiques sociales : vers un nouveau paradigme. Une méthodologie floue : la recherche participative." Pensée plurielle **28**(3): 23.
http://www.cairn.info/revue-pensee-plurielle-2011-3-page-11.htm

> La recherche participative, ainsi que l'ensemble des outils de l'analyse qualitative en sciences sociales, relève d'une méthodologie floue ou méthodologie de l'entre-deux. Celle-ci valorise la logique du tiers inclus, à la fois dans et hors de la réalité étudiée, concrète et abstraite. Elle est rigoureuse et fluide. Elle est particulièrement adaptée au paradigme du réseau fluide, qui s'impose comme l'image de base particulièrement riche de potentialités pour questionner la réalité complexe et fuyante du monde d'aujourd'hui, qu'on la qualifie de post- ou d'hypermoderne.

Gardien, È. (2017). "Qu'apportent les savoirs expérientiels à la recherche en sciences humaines et sociales ?" Vie sociale **20**(4): 31-44.
https://www.cairn.info/revue-vie-sociale-2017-4-page-31.htm

> Cet article apporte un ensemble de connaissances relatives à la nature des savoirs expérientiels et à leurs modalités sociales de production et de légitimation. Il montre en quoi chaque être humain est concerné par ces savoirs expérientiels. Dans le même temps, certains de ces savoirs présentent de véritables spécificités : une typologie des savoirs expérientiels issus des situations liées au handicap, à la maladie chronique ou aux troubles de la santé mentale est ainsi présentée. Une fois cette contextualisation effectuée, une réflexion sur les causes de la non-reconnaissance des savoirs expérientiels et une discussion sur les intérêts des sciences humaines et sociales à les prendre davantage en considération sont développées. La conclusion revient sur les limites d'un parti pris trop dogmatique sur l'usage des savoirs expérientiels dans le champ académique.

Gardien, È., Jaeger, M. et al., e. (2017). "L'implication citoyenne dans la recherche. Dossier." Vie sociale **20**(4): 7-238.

> En France, la reconnaissance à la fois de la possibilité et de la légitimité pour des personnes en difficulté non seulement de pouvoir être associées à des recherches, mais aussi à en produire elles-mêmes se heurte, à une conception restrictive du savoir scientifique et aux rigidités de certaines cultures professionnelles.

Giust-Desprairies, F. (2001). "De la recherche-action à l'intervention psychosociale clinique." Revue internationale de psychosociologie **VII**(16): 33-46.
https://www.cairn.info/revue-internationale-de-psychosociologie-2001-16-page-33.htm

> L'auteur se dégage d'une perspective lewinienne trop souvent comprise comme action de changement volontaire dans une visée où les changements seraient définis comme traitement des problèmes d'adaptation (la régulation comprise comme recherche de l'équilibre). La réticence de l'auteur tient à ce qui, dans cette approche, induit une représentation de la part du consultant sur le degré et les registres de satisfaction que doit atteindre le groupe. La démarche clinique se distingue de celle de la recherche-action dans la mesure où le chercheur n'est pas centré sur l'action mais sur la demande comme demande de sens qui définit un questionnement sur un rapport. Elle est une manière particulière d'interroger le faire-ensemble mais aussi l'être-

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ensemble au niveau des processus subjectifs et intersubjectifs, des logiques organisationnelles, institutionnelles et sociales et dans les agencements de ces processus et de ces logiques. L'objet de recherche se définit dans l'écart entre acteurs et chercheurs, compris non pas comme distancia tion critique, mais comme ce qui permet la relation sans laquelle l'analyse d'un certain type de processus ne pourrait avoir lieu.

Godrie, B. (2019). "Raconter sa déraison : émotions et crédibilité de la parole de représentants d'usagers en santé mentale." Sciences Sociales Et Santé **37**(1): 43-67.
https://www.cairn.info/revue-sciences-sociales-et-sante-2019-1-page-43.html

Cet article traite des liens qui unissent les émotions et la mobilisation de militants qui participent à un comité d'organisation des services de santé mentale d'un établissement du réseau de la santé au centre-ville de Montréal. La perspective historique fait ressortir un déplacement des espaces dans lesquels se jouent les luttes des militants pour la défense des droits en santé mentale. Auparavant actifs hors des cadres institutionnels au sein d'associations d'usagers, ces derniers intègrent de plus en plus des espaces de participation façonnés par les pouvoirs publics. Ce déplacement s'accompagne d'un discrédit de certaines émotions comme la colère et l'indignation qui ont pourtant servi de levier de transformation des institutions publiques.

Greacen, T. et Jouet, E. (2008). "Le projet Emilia : l'accès à la formation tout au long de la vie et la lutte contre l'exclusion." L'information psychiatrique **84**(10): 929.
http://www.cairn.info/revue-l-information-psychiatrique-2008-10-page-923.htm

Emilia (Empowerment of Mental Health Service Users through Life Long Learning, Integration and Action, [« Autonomisation des usagers des services de santé mentale par l'accès à la formation tout au long de la vie et l'intégration active »]) est un projet de recherche qui a pour objectif général de développer, mettre en place et évaluer une stratégie d'accès à la formation tout au long de la vie en vue de lutter contre l'exclusion sociale des personnes vivant avec un trouble de santé mentale. Emilia avance l'hypothèse que l'accès à la formation et à l'emploi améliorera l'insertion sociale et la qualité de vie des participants et diminuera leur utilisation des services sanitaires et sociaux. Financé par la Commission européenne et se déroulant dans le cadre d'ENTER Mental Health, un réseau européen d'établissements publics de santé et d'universités spécialisé dans les soins, la formation et la recherche en santé mentale, Emilia réunit 17 partenaires institutionnels dans 12 pays différents. La recherche, initiée en septembre 2005 et qui s'étendra sur une période de 54 mois, s'appuie sur deux aspects de la politique européenne que représentent le principe d'inclusion sociale et le droit à l'éducation et à la formation tout au long de la vie (Conseil de Lisbonne, mars 2000). L'article décrit les stratégies et pratiques actuellement mises en place pour s'appuyer sur les compétences acquises dans le parcours de soins dans une démarche de réinsertion sociale.

Jouet, E. (2013). "Le projet Emilia : inclusion sociale par la formation des personnes vivant avec un trouble psychique." Savoirs **31**(1): 80.
http://www.cairn.info/revue-savoirs-2013-1-page-69.htm

De 2005 à 2010, les participants au projet Emilia ont développé un programme de formation tout au long de la vie et d'accompagnement vers l'emploi dans le milieu ordinaire pour un groupe de personnes vivant avec un trouble psychiatrique. L'étude a analysé les effets sur la

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qualité de vie des usagers et sur leur utilisation des services sanitaires et sociaux de cette intervention basée sur les notions d'empowerment et de rétablissement. Les résultats suggèrent que les programmes d'insertion professionnelle et sociale des usagers de la psychiatrie devraient prendre en compte leurs compétences et leurs capacités d'autonomisation et de rétablissement. Un programme de formation tout au long de la vie adapté à leurs besoins d'usagers-experts et développant la notion de rétablissement facilite l'accès à l'emploi ordinaire et modifie les conditions de collaboration entre les différentes institutions impliquées.

Jouet, E. et Andrieu, B. (2016). "L'approche fondée sur le rétablissement : éducation diffuse et santé mentale." Le Télémaque **49**(1): 124.
http://www.cairn.info/revue-le-telemaque-2016-1-page-111.htm

Dans le contexte d'une injonction générale à l'autonomie, l'approche du "rétablissement" en santé mentale commence à se diffuser dans nos pays. En interrogeant ses fondements, qu'il s'agisse de la narration de soi, du pouvoir d'agir ou de l'auto-formation, cet article constate qu'ils participent de l'éducation diffuse. Ainsi, le "rétablissement" peut apparaître comme une démarche de valorisation et d'auto-validation des acquis de l'expérience des troubles chroniques. Celle-ci permet au patient de développer son pouvoir d'agir et de construire les moyens de s'engager au mieux dans un nouveau régime de vie, avec ses troubles, dans l'auto-formation. Cette approche a fait émerger des rôles de formation et de recherche pour certains malades. Le "rétablissement" étant à la fois apprentissage de la perte et art de re-vivre, il peut être conçu comme un analyseur essentiel, une hétérotopie de l'éducation en vue de l'acceptation de soi, des autres et du monde.

Jouet, E. et Greacen, T. (2009). "Psychologie communautaire et recherche : l'exemple du projet Emilia" Pratiques Psychologiques **15**(1): 77-88.

Le développement de la psychologie communautaire a entraîné à une réflexion sur les méthodes d'évaluation et de recherche. Le principe d'empowerment, c'est-à-dire le fait de donner à l'usager les moyens d'être acteur de sa santé et de prendre ses propres décisions concernant sa santé, a des implications non négligeables pour le choix des stratégies d'évaluation des actes de soins individuels comme pour des programmes de santé publique. Si nous reconnaissons l'expertise potentielle de l'usager en matière de soins, comment le faire en matière de recherche ? Comment l'usager peut-il devenir acteur non seulement de sa santé, mais aussi de la recherche et de l'évaluation en matière de santé ? L'article donne un aperçu de quelques stratégies de recherche s'appuyant sur les principes de la psychologie communautaire et, notamment, la recherche–action et la recherche action participative. L'exemple d'une étude multisite européenne sur l'accès des personnes vivant avec un trouble de santé mentale à l'éducation, à la formation tout au long de la vie et à l'emploi, actuellement en cours à Paris, est présenté en tant qu'illustration de ces méthodologies communautaires de recherche.

Kovess-Masféty, V. et Villani, M. (2019). "Aidants profanes en psychiatrie et politiques sociales." Revue française des affaires sociales(1): 55-74.
https://www.cairn.info/revue-francaise-des-affaires-sociales-2019-1-page-55.htm

Le rôle des aidants profanes en santé mentale s'est considérablement accru suite à la désinstitutionnalisation, la famille et les proches des patients se voyant alors assigner un rôle désormais central, celui d'aidants dits « naturels ». Malgré un certain nombre d'aides sociales,

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destinées d'abord au patient, mais aussi à ses aidants, les familles déclarent en bénéficier très peu et se sentir relativement seules face à la gestion quotidienne de la maladie. Outre cet enrôlement forcé, les familles et les proches font parfois le choix d'apporter leur aide bénévolement, dans le but de soutenir d'autres familles et des usagers confrontés à une situation similaire à la leur. Ces actions d'entraide s'inscrivent dans la mouvance des philosophies du self-help, sur la base de laquelle les usagers de la psychiatrie eux-mêmes ont fait émerger la notion de « pairs aidants », ces derniers venant contribuer au rétablissement d'autres usagers dans le cadre de programmes d'entraide informels ou structurés. Certains de ces programmes ont récemment promu une fonction d'aidant professionnalisée et rémunérée, dont la reconnaissance se fonderait sur un savoir expérientiel, à la limite entre profane et professionnel. Cette innovation a provoqué de vifs débats et porte de nombreux enjeux. Quoi qu'il en soit, le dynamisme des associations d'usagers et de familles devrait pouvoir s'appuyer sur la volonté des politiques publiques de créer les conditions du développement et du soutien des aidants profanes en santé mentale.

Las Vergnas, O., Jouet, E. et Renet, S. (2017). "Entre reconnaissance des savoirs expérientiels des malades et coopérations réflexives collectives : un point d'étape bibliométrique." Politiques de communication **9**(2): 117-161.
https://www.cairn.info/revue-politiques-de-communication-2017-2-page-117.htm

Les discours sur la participation des patients et sur le développement des coopérations entre usagers de la santé et professionnels se multiplient à l'heure actuelle. Ils suggèrent que nos systèmes de santé sont en transition entre deux époques : la première a été celle de la reconnaissance des savoirs expérientiels des malades ; la seconde, annoncée comme imminente, serait celle d'une systématisation des coopérations réflexives de tous types entre malades, groupes de malades et professionnels. Par des analyses bibliométriques des termes concernant la « participation des patients » dans les publications biomédicales, cet article vise à objectiver cette situation intermédiaire. Trois investigations sont déployées dans ce but : le repérage des publications indexées par les mots-clés « participation », « involvement » et « engagement » dans la base de données bibliographique biomédicale

Launat, D. (2020). "De qui suis-je le pair ?" Pratiques en santé mentale **66e année**(3): 40-49.
https://www.cairn.info/revue-pratique-en-sante-mentale-2020-3-page-40.htm

Dominique Launat interroge d'abord la parité, fort de sa longue expérience en tant que psychologue en psychiatrie publique : de qui suis-je le pair ? Réponse : incertitude sur les collègues, soignants ou autres, opposée à une certitude : pairs, ceux que je reconnais comme tels. Autre élément de certitude : si l'exigence de parité s'avère indispensable pour tout un chacun, elle l'est d'autant plus dans le champ de la maladie mentale, impératif pour rester au monde.En tant que délégué du Collectif National Inter Groupes d'Entraide Mutuelle (CNIGEM), l'auteur a une vive conscience de cet impératif. Pour désigner la relation entre les adhérents d'un GEM, il préfère la qualification d'entraide à celle de pair-aidance. Entraide traduit mieux les diverses modalités d'être ensemble, avec leurs niveaux et moments variables de parité .Position prudente aussi par rapport à la professionnalisation de la pair-aidance, eu égard au poids et l'influence de tout collectif dans une institution. Sa connaissance des GEM, des rapports de solidarité et de citoyenneté qui les traversent, lui fait mettre l'accent sur la réciprocité potentielle attachée prioritairement à l'entraide.

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Loretti, A. (2020). "« Ces patients qui ne font pas ce qu'il faut ». Étude des impacts de la moralité sanitaire dans la prise en charge des corps malades en cancérologie." Revue française des affaires sociales(3): 33-49.
https://www.cairn.info/revue-francaise-des-affaires-sociales-2020-3-page-33.htm

> La santé publique s'intéresse de manière croissante aux comportements individuels. De plus en plus d'interventions visent à favoriser des « conduites vertueuses » et à transformer les comportements. Si ces politiques sont considérées comme éthiquement justifiées parce qu'elles agissent pour le « mieux-être » de la population, elles font aussi l'objet de critiques liées à leur normativité et certains chercheurs ont pu décrire la santé publique comme une entreprise de moralisation des comportements de santé. À partir d'une enquête par observations et entretiens portant sur la prise en charge de patients atteints de cancers, cet article propose de traiter des conséquences pratiques de la moralité sanitaire en cancérologie. Plus précisément, nous nous intéresserons à la réception des normes de « bonne gestion » de son corps par les patients et les soignants, puis nous nous pencherons sur leur traduction dans la prise en charge des corps malades.

Loubières, C., Caria, A. et Arfeuillère, S. (2018). "Prendre la parole pour déconstruire les idées reçues sur les troubles psychiques. Le savoir d'expérience pour agir contre la stigmatisation en santé mentale." L'information psychiatrique **94**(10): 809-816.
https://www.cairn.info/revue-l-information-psychiatrique-2018-10-page-809.htm

> RésuméPrendre la parole pour déconstruire les idées reçues sur les troubles psychiques. Agir contre la stigmatisation en santé mentale est un processus lent et complexe qui nécessite d'écouter la parole des personnes concernées par un trouble psychique. Car mettre un visage sur une maladie impose une alternative à la déshumanisation liée aux mécanismes de stigmatisation, et entendre le récit des personnes permet d'envisager les troubles psychiques au travers d'expériences singulières, évitant toute généralisation. Il convient toutefois de penser cette prise de parole publique à trois niveaux :– sa méthode : en construisant le récit selon des objectifs pédagogiques ;– son approche éthique : en questionnant un rapport égalitaire des savoirs (professionnel et d'expérience), les postures des uns et des autres, mais aussi la place laissée à chacun ;– sa progression : il existe différents niveaux de participation.Cet article propose quelques repères issus de l'expérience du Psycom d'accompagnement à la prise de parole publique de personnes concernées par des troubles psychiques.

Lyet, P. (2011). "Traduction, transaction sociale et tiers intermédiaire dans les processus de collaboration de chercheurs et de praticiens dans le cadre de recherches-actions." Pensée plurielle **28**(3): 67.
http://www.cairn.info/revue-pensee-plurielle-2011-3-page-49.htm

> La question des tiers intermédiaires dans les processus de collaboration de chercheurs et de praticiens conduit à interroger tout d'abord la dynamique des espaces où se jouent ces collaborations. Nous le faisons grâce à un modèle d'analyse qui croise deux couples d'opposition – le couple connaissance-action et le couple généralité-singularité – et identifie les jeux de tension qui s'y développent. Nous pouvons alors identifier quatre logiques idéal-typiques : la théorisation, l'analyse, la modélisation et la pratique qui, associées deux à deux, permettent de construire quatre cas de figure idéal-typiques de pratiques : la recherche académique, la recherche appliquée, la recherche-intervention et la préconisation.Deux collaborations

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chercheurs-praticiens sont soumises à cette grille d'analyse. Les collaborations s'y développent dans une articulation entre les logiques de la modélisation et de l'analyse et elles conduisent les chercheurs à investir de temps en temps la logique de la théorisation et les praticiens la logique de la pratique de terrain. Selon des dynamiques non similaires, une circularité se construit, d'une part, entre les quatre logiques mais en activant plus fréquemment celles de la modélisation et de l'analyse ; et, d'autre part, entre les quatre cas de figure de pratiques proposées, mais en activant plus fréquemment le couple recherche appliquée/recherche-intervention. Les passages qui se construisent entre ces différentes logiques conduisent les acteurs de ces processus à développer des opérations de traduction et de transaction sociale. Ils peuvent le faire parce qu'ils sont coutumiers de ces passages. Nous n'avons pas affaire à des tiers intermédiaires mais à des acteurs traducteurs engagés dans un processus de traduction croisée et de transaction sociale.

Martin, B. (2017). "Empowerment et liberté en psychiatrie." Perspectives Psy **56**(3): 211-216.
https://www.cairn.info/revue-perspectives-psy-2017-3-page-211.htm

Les travaux contemporains sur l'empowerment (autodétermination) mettent l'accent sur la promotion de la liberté du sujet comme levier du processus de rétablissement. Nous proposons dans cet article de revenir sur les enjeux psychiques de l'exercice de la liberté, tels que la psychologie existentielle et humaniste les a analysés. La liberté, source d'épanouissement pour le sujet, s'avère également un exercice difficile pour chacun de nous. En effet, loin de constituer une panacée, son exercice s'avère une tâche ardue qui implique la confrontation du sujet à sa propre mort, à la solitude et à la question du sens. Par conséquent, si l'invitation à une modification du fonctionnement des institutions psychiatriques dans le sens d'un plus grand respect de la liberté des personnes constitue un apport des travaux sur le rétablissement, l'exercice de la liberté (empowerment) requiert également l'attention du soignant, et peut, dans certains cas, constituer la cible d'un authentique un travail psychothérapeutique.

Maugiron, P. (2020). "Les différentes modalités qui déterminent l'accompagnement par les pairs." Pratiques en santé mentale **66e année**(3): 20-25.
https://www.cairn.info/revue-pratique-en-sante-mentale-2020-3-page-20.htm

Philippe Maugiron, professionnel de la pair-aidance, présente trois aspects, chacun précisément documenté.Le premier intéresse les origines de la pair-aidance, en comparant la situation américaine et française. Il relève qu'en France, les premiers groupes de personnes concernées, liées à une expérience psychiatrique se sont organisés plus tardivement sous l'influence de l'UNAFAM (1963) et du GIA (1972-1974).Le second s'intéresse à la professionnalisation de la pair-aidance : même retard pour la France. En 2012, le Centre Collaborateur de l'Organisation Mondiale de la Santé (CCOMS) a porté le premier projet de médiateurs de santé pairs.Le troisième dresse un panorama actuel des formations professionnalisantes (à Paris, Lyon, Marseille et Lille) avec descriptif des formations et leurs références.

Murray, M. et Foucart, J. (2012). "Psychologie communautaire de la santé, arts et changement social. Panorama dans le monde anglo-saxon." Bulletin de psychologie **Numéro 521**(5): 427.
http://www.cairn.info/revue-bulletin-de-psychologie-2012-5-page-419.htm

L'approche communautaire, en psychologie de la santé, a évolué durant ces dix dernières années, s'inspirant de différents courants inscrits dans la psychologie critique, dans l'activisme

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social et dans la santé publique. L'approche communautaire s'intéresse aux travaux avec des groupes et des communautés, et se focalise sur la transformation de leurs conditions de vie et de travail. Cet article retrace le développement de cette approche dans le monde anglo-saxon en mettant l'accent sur le rôle de l'art et des activités artistique dans le cadre d'un pouvoir d'action des sujets.

Noël-Hureaux, E. (2019). "De l'expérience singulière médiatisée de la maladie à la construction de savoirs expérientiels." Recherche en soins infirmiers **138**(3): 65-74. https://www.cairn.info/revue-recherche-en-soins-infirmiers-2019-3-page-65.htm

> À travers la figure publique et charismatique d'un acteur et écrivain célèbre, Bernard Giraudeau, nous proposons d'explorer en quoi une telle expérience singulière médiatisée et confrontée à d'autres peut devenir source de savoirs expérientiels. Pour ce faire, nous analyserons les différentes formes de communication associées à des supports aussi variés que la presse écrite ou les blogs rendant visibles l'empowerment dans l'agencement des interactions.

Niard, C. et Franck, N. (2020). "Apports de la pair-aidance aux dispositifs de santé mentale en France. Quelles formes de pair-aidance pour quels objectifs ?" Pratiques en santé mentale **66e année**(3): 50-57. https://www.cairn.info/revue-pratique-en-sante-mentale-2020-3-page-50.htm

> Tant Camille Niard, médiatrice de santé paire, que Nicolas Franck, Professeur de psychiatrie, tournent leur projecteur sur la professionnalisation des pairs-aidants en santé mentale. Ils dressent un état des lieux de leur nombre, de leurs formations et de leurs objectifs.Ces derniers se recommandant historiquement de cette pratique dite Recovery ou Rétablissement, initiée aux USA par « Les survivants de la psychiatrie » dans les années 1970. La pair-aidance « affirme que la vulnérabilité psychique peut s'apprivoiser, être dépassée et devenir une force pour la personne et, au-delà, pour la société ».Deux originalités aussi à retenir dans cet article centré sur le Rétablissement. D'une part, il existe une association intitulée « ESPAIRS » (tout l'espoir promu par les pairs), collectif autogéré de pairs, au service des institutions, mais hiérarchiquement indépendantes d'elles. D'autre part, depuis 2019, a été mis en place un Observatoire du Rétablissement, animé par des pairs et financé par la Fondation de France.

Nolte, E., et al. (2017). "Placer la personne au centre de la démarche de soins : analyse et évolution des notions de patient-centredness et person-centredness et de leur signification dans le domaine de la santé." Revue française des affaires sociales **42**(1): 115. http://www.cairn.info/revue-francaise-des-affaires-sociales-2017-1-page-97.htm

> Le numéro de janvier-mars 2017 de la Revue française des affaires sociales comprend tout d'abord un dossier sur « Le patient et le système de santé » coordonné par Marianne Berthod-Wurmser, Frédéric Bousquet et Renaud Legal. L'appel à contribution proposait trois axes de réflexion : la prise en compte de la personne qu'est le patient par les institutions et les professionnels de santé ; l'évolution des compétences, comportements, attitudes, attentes et obligations des patients ; la démocratie sanitaire et la place des usagers dans le fonctionnement du système de santé. Quatre articles ont été sélectionnés. Ils sont suivis de plusieurs éléments. D'une part, des contributions qui visent à définir les notions de patient-centredness et de person-centredness (Observatoire européen des systèmes et politiques de santé), à proposer un tour d'horizon international de la participation des usagers aux systèmes de santé et à approfondir la politique britannique d'implication des patients et du public (Véronique Ghadi et

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Frédéric Bousquet). D'autre part, trois entretiens ont été réalisés auprès de Didier Tabuteau, de Claire Compagnon et de l'association Renaloo. Puis, après une présentation des Plans cancer est évoquée la place des patients dans les parcours de prise en charge de cette maladie.Enfin, une revue de littérature développe le thème de l'accès aux soins. Deux autres articles figurent dans ce numéro : le premier sur l'évolution des conceptions du système de protection sociale et le second sur l'Obamacare.

Peljak, D. (2016). "Empowerment en santé mentale : pour une évolution du droit sanitaire français." Revue française des affaires sociales(2): 88.
http://www.cairn.info/revue-francaise-des-affaires-sociales-2016-2-page-75.htm

Sous l'influence des normes internationales et du juge, le législateur français a fait évoluer la loi en faveur de l'empowerment des personnes souffrant de troubles mentaux, en modifiant le rapport soignant/soigné : intervention systématique du juge des libertés pour les personnes hospitalisées sous contrainte (qui peuvent également saisir le contrôleur général des lieux de privation de liberté), obligation d'information et d'association du patient au programme de soins, évolution du régime des tutelles, reconnaissance de la notion d'éducation thérapeutique ... Cependant, malgré certaines expériences très intéressantes et malgré les évolutions juridiques récentes en faveur de l'empowerment individuel, l'arsenal juridique français est largement limité aux questions d'hospitalisation sous contrainte, de tutelle et de libertés individuelles et demeure balbutiant au regard des expériences de terrain d'empowerment collectif. L'auteur souligne la nécessité de faire encore évoluer le droit codifié français par une reconnaissance législative ou réglementaire des structures visant à déstigmatiser la maladie et à mieux coordonner les acteurs de terrain (maisons de santé, conseils locaux de santé mentale ...) ou en rendant plus perméables certaines frontières juridiques (voir séparation entre le sanitaire et le médico-social).

Pelletier, J. F. et Caron, J. (2015). "Partenariats patients en santé mentale." Santé mentale au Québec **40**(1): 274.
https://www.erudit.org/fr/revues/smq/2015-v40-n1-smq02004/

Ce numéro thématique de Santé mentale au Québec propose de revenir à une conception plus égalitaire et fraternelle dans les relations patients/soignants. Relations permettant à plusieurs personnes en détresse de retrouver un sens de la dignité et de la citoyenneté. Ce numéro relate des expériences et tentatives citoyennes en santé mentale en provenance de différents coins du monde, du Brésil, de l'Écosse, de la France et du Québec.

Pernin, T., Sahier, C., Monotuka, S., et al. (2018). "Savoir reconnaître le savoir expérientiel des patients : une humilité et une force pour le médecin généraliste." Medecine : De La Medecine Factuelle a Nos Pratiques **14**(1): 19-22.

Bien que formulée par les textes réglementaires, l'implication de patients dans les activités d'éducation thérapeutique du patient (ETP) reste faible en France. De nombreuses publications internationales soulignent le savoir expérientiel des patients-ressources, la construction de partenariats avec les soignants et l'amélioration de l'état de santé de patients ciblés grâce à leur intervention. Le réseau Paris Diabète (RPD) intègre des patients dans sa gouvernance et cherche à les impliquer dans l'animation de ses programmes d'ETP.

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Pomey, M.-P., Flora, L., Karazivan, P., et al. (2015). "Le "Montreal model" : enjeux du partenariat relationnel entre patients et professionnels de la santé." Santé Publique **27**: 41-50, fig.

[BDSP. Notice produite par EHESP R0x8Am9l. Diffusion soumise à autorisation]. Depuis 2010, un nouveau modèle relationnel, basé sur le partenariat entre les patients et les professionnels de la santé, a été développé à la Faculté de médecine de l'Université de Montréal. Ce modèle de partenariat patient s'appuie sur la reconnaissance des savoirs expérientiels du patient, issus de la vie avec la maladie, et complémentaires des savoirs scientifiques des professionnels de la santé. Il s'inscrit dans un continuum d'engagement des patients et peut s'appliquer dans les milieux de soins, de la formation des professionnels, de l'enseignement et de la recherche. Les fondements théoriques du partenariat patient sont exposés ici, ainsi que la manière dont ce nouveau modèle peut être mis en oeuvre aux niveaux clinique, organisationnel et systémique et quels en sont les facteurs de réussite tant du côté des patients que des professionnels de la santé.

Rat, C., Peteuil, A., Reynaud, M., et al. (2019). "Un partenariat patients schizophrènes-soignants pour conduire un programme d'éducation en santé orale." Santé Publique **31**(3): 405-415.
https://www.cairn.info/revue-sante-publique-2019-3-page-405.htm

Introduction : La mauvaise santé orale des patients schizophrènes est un problème de santé publique qui concernerait 600 000 personnes en France. Le but de cet article est de présenter les différentes étapes de la construction d'un programme d'éducation en santé orale, spécifique aux patients schizophrènes et tenant compte de leur savoir expérientiel, ainsi que les résultats de l'étude pilote ce programme. Patients et méthode : La méthode des groupes de discussion (focus groups) a été appliquée à un groupe de professionnels de santé et d'usagers afin de faire émerger un corpus exploratoire pour la construction d'un programme d'éducation en santé orale. Un groupe expert composé pour partie de patients schizophrènes a validé les thématiques et les outils de ce programme. Une étude pilote de faisabilité a ensuite été réalisée auprès d'un groupe témoin composé de sept patients schizophrènes. Résultats : Au total, 26 personnes ont participé à cette étude. Les thématiques principales retenues par le groupe expert visent à favoriser l'action consistant à prendre soin de sa santé, à améliorer la pénétrabilité du système de soins et à promouvoir une approche sanitaire globale. L'étude a montré la capacité des acteurs à coconstruire un programme et à faire évoluer les représentations que les patients schizophrènes ont de ce problème de santé. La plupart des outils éducatifs ont été jugés pertinents. Conclusion : Un programme d'éducation en santé orale a été construit dans le cadre d'un partenariat patients-soignants et a montré sa faisabilité. Une étude randomisée multicentrique est en cours pour évaluer l'efficacité de ce programme avec un haut niveau de preuve.

Rey, S., Savoie, C., Voyer, P., et al. (2020). "Fondamentaux des soins : un cadre et un processus pratique pour répondre aux besoins physiques, psychosociaux et relationnels des personnes soignées." Recherche en soins infirmiers **142**(3): 7-30.
https://www.cairn.info/revue-recherche-en-soins-infirmiers-2020-3-page-7.htm

Depuis 2008, un regroupement international soutient la promotion d'une meilleure réponse aux besoins fondamentaux des personnes soignées. Ce regroupement propose un cadre sur les fondamentaux des soins. Ce cadre est centré sur la relation entre l'infirmier, la personne soignée et ses proches ainsi que sur la réponse aux besoins physiques, psychosociaux et

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relationnels. Un processus pratique soutient l'application concrète de ce cadre. Le but de cet article discursif est de présenter la traduction française du cadre des fondamentaux des soins et de son processus pratique. Pour commencer, le processus de traduction sera brièvement expliqué. Ensuite, le cadre sur les fondamentaux des soins et les étapes de son processus pratique seront présentés. Afin de permettre une meilleure appropriation du contenu par le lecteur, une illustration clinique présente la situation de M. Perron, atteint d'une maladie d'Alzheimer, et de sa conjointe, qui est sa proche aidante. Enfin, la discussion aborde l'utilité du cadre des fondamentaux des soins et de son processus pratique au niveau des quatre grands axes de la discipline infirmière, soit la pratique, la gestion, la formation et la recherche. Cet article ouvre la voie au développement de connaissances sur les fondamentaux des soins au niveau de la francophonie.

Roelandt, J. L. (2019). "Implications des usagers en santé mentale : un défi permanent. Commentaire." Sciences Sociales Et Sante **37**(1): 69-74.

Quel est le parti pris des sciences sociales et psychologiques lorsqu'elles parlent de la colère, de l'indignation et de la revendication en faisant référence aux « émotions » ? N'est-ce pas, d'une certaine façon, mélanger sphère sociale et sphère intime et donner, subrepticement, le primat à cette dernière ? N'est-ce pas orienter le regard vers l'individu et son vécu, son éventuelle position de victime, plus que vers l'acteur ou l'actrice engagé.e dans la transformation sociale ? Les deux sont certainement liés car les actions des militant.e.s ont souvent des bases émotionnelles, psychologiques. L'amélioration de la société et des humains qui la composent se fera par l'élimination de la violence physique, psychique et politique - symbolique ou réelle - et cela demeure avant tout un combat.

Roelandt, J.-L. (2010). "De la psychiatrie vers la santé mentale, suite : bilan actuel et pistes d'évolution." L'information psychiatrique **86**(9): 783.
http://www.cairn.info/revue-l-information-psychiatrique-2010-9-page-777.htm

La psychiatrie est la discipline médicale la plus liée à l'organisation sociale et politique de la société dans laquelle elle se met en œuvre. Depuis 50 ans, a été confié à la psychiatrie seule (et malheureusement seule) l'ensemble de la question de la santé mentale – prévention, post-cure, réadaptation et soins. Or, cette question ne peut se concevoir qu'avec la participation de toute la société et de la médecine dans son ensemble : soins de santé primaire, logement, travail et insertion, loisirs, familles et environnement social, justice et police. L'enjeu est ici de réintroduire la question de la santé mentale, en tant qu'élément de la santé publique, dans le débat politique et social.

Salles, J., Levasseur, D., Yrondi, A., et al. (2020). "L'hôpital de jour de psychiatrie à l'ère du numérique : les propositions d'un patient expert." L'information psychiatrique **96**(5): 363-367.
https://www.cairn.info/revue-l-information-psychiatrique-2020-5-page-363.htm

Les hôpitaux de jours font partie du paysage psychiatrique depuis la naissance des secteurs et leur utilité dans le parcours de soin des patients n'est plus à démontrer. Pour autant les nouvelles générations habituées aux media numériques peinent parfois à trouver leur place dans des activités pensées avant la naissance de ces innovations technologiques. Dans notre structure, les patients ont pu faire le constat que les activités médiatisées ne s'étaient que trop timidement saisies des champs créatifs et communicatifs générés par ces outils connectés. Ce

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constat est d'autant plus regrettable que ces nouvelles technologies ouvrent des voies inédites et permettent de repenser les prises en charge et la relation soignant soigné.Nous avons donc fait appel à un patient expert afin de préciser quels axes d'améliorations pouvaient être envisagés pour intégrer le numérique aux activités de notre structure. Ce patient expert fait partie de la génération connectée, il a pu faire plusieurs propositions pour le développement des activités numériques au sein des activités proposées à l'heure actuelle. Les propositions du patient expert ont ensuite été adaptées aux possibilités de mise en œuvre pratique compte tenu des facteurs budgétaires et organisationnels.

Schweitzer, L. (2020). "« On est des (ex-) quelque chose »… De la mobilisation des savoirs expérientiels dans le travail pair." Rhizome **75-76**(1): 56-66.
https://www.cairn.info/revue-rhizome-2020-1-page-56.htm

Terral, P. (2020). "Développer une science des solutions pour les interventions en santé en France : les RISP, un espace intermédiaire de pluralisation des expertises." Revue française des affaires sociales(4): 53-72.
https://www.cairn.info/revue-francaise-des-affaires-sociales-2020-4-page-53.htm

> En prenant pour terrain d'enquête les recherches interventionnelles en santé des populations (RISP), un domaine de recherche émergeant dans le secteur de la santé en France, cette contribution se propose de considérer divers jeux d'acteurs et d'arguments, de pouvoir et de savoir qui accompagnent son développement. Nous montrons que ce nouvel espace intermédiaire, entre l'expérimentalisme et les sciences humaines et sociales, œuvre à une pluralisation des expertises en santé pour une meilleure prise en compte de la singularité des contextes des interventions, de la transférabilité des connaissances. Il met également en avant la volonté de renforcer les collaborations entre chercheurs et « acteurs de terrain ». Nous soulignons toutefois combien ces deux grands principes donnent lieu à des appréhensions et à des positionnements différents rendant compte d'approches différenciées des recherches interventionnelles en France. L'enquête se base sur trois grands types de données : des observations ethnographiques de RISP ainsi que des congrès et réunions de groupes d'experts produisant des réflexions sur ce type de recherches, des analyses d'écrits (articles, rapports, lettres d'information…) sur les RISP et des entretiens (14) avec les principaux experts du domaine.

Véron, P. (2020). "Les décisions de soins en contexte de vulnérabilité : quels arbitrages du droit entre autonomie et contrainte ?" Sciences Sociales Et Santé **38**(2): 67-75.
https://www.cairn.info/revue-sciences-sociales-et-sante-2020-2-page-67.html

> Inspirée du modèle nord-américain de la shared decision-making (Charles et al., 1997 : 681), la décision médicale partagée fait l'objet d'une attention croissante en France depuis une vingtaine d'années, dans les discours institutionnels (HAS, 2013) et dans une moindre mesure dans les pratiques de soins, en particulier la prise en charge des maladies chroniques (Boulenc et Poisson, 2014 : 4). En droit médical français, elle fait désormais figure de règle de principe. Le code de la santé publique dispose depuis 2002 que « toute personne prend, avec le professionnel de santé et compte tenu des informations et des préconisations qu'il lui fournit, les décisions concernant sa santé ». Cette exigence générale s'incarne plus concrètement dans le droit du patient d'être informé sur les actes qui lui sont proposés et d'y donner un consentement éclairé. Le patient doit ainsi pouvoir discuter des différentes alternatives

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diagnostiques et thérapeutiques, au regard de ses priorités, besoins et préférences. La codécision s'inscrit dans la tendance plus générale à promouvoir à la fois l'autonomie du patient, acteur de sa santé, et l'expertise profane. Cette autonomie n'a cependant rien d'évident. Elle est à construire.

Études étrangères

OUVRAGES

(2019). Participation des enfants et adolescents dans le domaine des soins de santé mentale. Bruxelles Conseil supérieur de la santé : 50.
https://www.health.belgium.be/fr/avis-9458-sante-mentale-et-jeunes

> La participation et l'implication des enfants dans les décisions qui les concernent est un droit fondamental, inscrit dans plusieurs textes législatifs. En plus d'être une fin en soi, c'est aussi un excellent moyen d'améliorer l'accessibilité, la qualité et l'efficacité des soins en rendant ceux-ci plus adaptés aux besoins. Mais la participation des enfants dans le domaine de la santé mentale est à l'heure actuelle quasi inexistante en Belgique. Alors que les problèmes de santé mentale constituent une part importante de la morbidité chez les enfants et les adolescents, il n'y a pas de groupe organisé qui représente leur voix dans ce domaine et il n'existe pas de cadre suffisant pour mettre en place un processus de participation. Dans cet avis, le CSS identifie les conditions nécessaires pour garantir le droit à la participation des enfants et des jeunes dans les soins de santé mentale, au niveau de l'aide individuelle, de l'organisation des services et de la politique gouvernementale.

Carrier, S., Morin, P., Gross, O., et al. (2017). L'engagement de la personne dans les soins de santé et services sociaux : regards croisés France-Québec. Montréal : Presses de l'Université du Québec

> La valorisation des savoirs expérientiels, la coproduction et l'évaluation des effets sont des concepts de plus en plus présents dans les réflexions touchant l'intervention médicale ou psychosociale. Ces notions forment un nouveau paradigme: rattachées à des approches générales comme la personnalisation ou à des méthodes de travail comme le patient partenaire ou l'éducation thérapeutique, elles favorisent les partenariats et les échanges entre la recherche, la clinique, les utilisateurs de services et l'enseignement. Le présent ouvrage est né des Rencontres scientifiques universitaires Montpellier- Sherbrooke, tenues en juin 2015, pendant lesquelles chercheurs, gestionnaires, intervenants et bénéficiaires se sont réunis pour réfléchir et débattre sur le thème de la participation et de l'engagement des usagers dans leur propre expérience d'intervention médicale ou psychosociale. Il met en perspective des pratiques, des recherches, des projets et des expériences issus du champ de la santé et de celui des services sociaux, tant en France qu'au Québec. Il saura intéresser les praticiens, chercheurs, étudiants et gestionnaires de ces deux domaines d'intervention.

Fieldhouse, J. (2017). Exploring the applicability of participatory action research in community mental health care in the UK. Faculty of Health and Applied Sciences > Department of Allied Health Professions. Bristol : University of the West of England, University of the West of England.
http://eprints.uwe.ac.uk/25601/36/DPhil%20Thesis%20-%20Jon%20Fieldhouse.pdf

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The aim of this thesis is what participatory action research (PAR) has to offer community mental health service development in the United Kingdom.

Kindon, S. et al. (2010). Participatory action research approaches and methods : connecting people, participation and place, New York : Routledge
http://www.amazon.com/Participatory-Action-Research-Approaches-Methods/dp/0415405505

Participatory Action Research (PAR) approaches and methods have seen an explosion of recent interest in the social and environmental sciences. PAR involves collaborative research, education and action which is oriented towards social change, representing a major epistemological challenge to mainstream research traditions. It has recently been the subject of heated critique and debate and rapid theoretical and methodological development. This book captures these developments, exploring the justification, theorisation, practice and implications of PAR. It offers a critical introduction to understanding and working with PAR in different social, spatial and institutional contexts. The authors engage with PAR's radical potential, while maintaining a critical awareness of its challenges and dangers. The book is divided into three parts. The first part explores the intellectual, ethical and pragmatic contexts of PAR; the development and diversity of approaches to PAR; recent poststructuralist perspectives on PAR as a form of power; the ethic of participation; and issues of safety and well-being. Part two is a critical exploration of the politics, places and practices of PAR. Contributors draw on diverse research experiences with differently situated groups and issues including environmentally sustainable practices, family livelihoods, sexual health, gendered experiences of employment, and specific communities such as people with disabilities, migrant groups, and young people. The principles, dilemmas and strategies associated with participatory approaches and methods including diagramming, cartographies, art, theatre, photovoice, video and geographical information systems are also discussed. Part three reflects on how effective PAR is, including the analysis of its products and processes, participatory learning, representation and dissemination, institutional benefits and challenges, and working between research, action, activism and change.The authors find that a spatial perspective and an attention to scale offer helpful means of negotiating the potentials and paradoxes of PAR. This approach responds to critiques of PAR by highlighting how the spatial politics of practising participation can be mobilised to create more effective and just research processes and outcomes. The book adds significant weight to the recent critical reappraisal of PAR, suggesting why, when, where and how we might take forward PAR?s commitment to enabling collaborative social transformation (4e de couverture).

Koch, T. et Kralik, D. (2009). Participatory action research in health care, John Wiley & Sons

Participatory Action Research in Healthcare provides a guide to participatory action research in the community health setting. It draws upon the authors' experiences working, researching and engaging with people utilising collaborative, participatory approaches. The authors position participatory action research as a vital, dynamic and relevant approach that can be engaged by practitioners and health service providers. It is argued that participating with people is the way to move forward toward sustainable services that evoke human flourishing. Participatory Action Research in Healthcare explores the key issues surrounding participatory action research, and examines the benefits of this approach for community development and health promotion. It includes detailed guidelines on data generation and analysis.

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www.irdes.fr/documentation/syntheses/la-recherche-participative-en-sante-mentale.epub

Minkler, M. et Wallerstein, N. (2011). Community-based participatory research for health: From process to outcomes, John Wiley & Sons

>   Minkler and Wallerstein have pulled together a fantastic set of contributions from the leading researchers in the field. In addition to a fine collection of case studies, this book puts the key issues for researchers and practitioners in a historical, philosophical, and applied, practical context

Park, P. (2006). "Knowledge and participatory research." Handbook of action research **2**: 83-93.
https://books.google.fr/books?hl=fr&lr=&id=oSTkb90xof0C&oi=fnd&pg=PA83&dq=Knowledge+and+participatory+research&ots=3p8po3MDRT&sig=oCOy865TWxcuS0QhbIW2F5_EN1c#v=onepage&q=Knowledge%20and%20participatory%20research&f=false

Prud'Homme, J. é. et Claveau, F. é. (2018). Experts, sciences et sociétés, Montréal : Les Presses de l'Université de Montréal (PUM)
https://pum.umontreal.ca/catalogue/experts-sciences-et-societes

>   Au vu de la place dominante qu'occupent les experts dans notre société, le citoyen peut être amené à se demander ce qu'est un expert et sur quel socle repose son autorité. Comment peut-il évaluer sa crédibilité, et à qui se vouer dans les cas (fréquents) où plusieurs experts divergent d'opinion ? Cet ouvrage collectif présente le personnage social de l'expert, les usages sociopolitiques de son travail ainsi que les manières d'arbitrer ses prétentions dans notre société. Une des grandes forces de ce livre tient à son caractère multidisciplinaire, qui accorde une place importante à la philosophie, à la science politique, à l'histoire, à la sociologie et aux sciences de la communication. Chaque texte offre un état de la question sur un volet précis et donne des clés d'explication à des problèmes actuels : contestation de la statistique publique, place des valeurs et des citoyens dans les décisions publiques, rôle social de la science, régulation des groupes professionnels ou rapports de pouvoir dans les espaces numériques (extrait 4e de couv.)

Van der Borght, C., et al. (2011). Les fonctions d'analyse des pratiques, de formation et de recherche. Éduquer et soigner en équipe. Louvain-la-Neuve
http://www.cairn.info/eduquer-et-soigner-en-equipe--9782804165970-page-191.htm

>   Les institutions soignantes ou éducatives, résidentielles ou non, qu'elles concernent des adultes, des enfants ou des adolescents, restent un terrain privilégié de recherche et de formation. Sur base de leur expérience plurielle, neuf acteurs de la vie institutionnelle développent dans cet ouvrage les problématiques essentielles qui se posent aux praticiens, quels que soient leur place et leur statut : organiser la vie d'un groupe d'utilisateurs et d'une équipe multidisciplinaire, définir les fonctions et les rôles, penser les modalités d'un soin psychothérapeutique à plusieurs, inscrire le travail dans le champ social et familial, etc. Ces thématiques s'articulent et se conjuguent selon une grammaire particulière à chaque projet institutionnel, pour que le travail y soit abordé tant au niveau global que dans ses singularités. Ainsi se dessine une vie institutionnelle où chacun joue son rôle dans une dynamique collective visant à accroître les possibilités de tous, tout en restant conscient des responsabilités et des limites de chacun. Pratique, Éduquer et soigner en équipe intéressera l'ensemble des professionnels exerçant en institution : éducateurs, directeurs, psychologues, infirmiers, personnel paramédical, assistants

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sociaux, psychiatres ou enseignants spécialisés. Il offrira également une aide précieuse aux étudiants en formation dans ces domaines.

ARTICLES

Abayneh, S., Lempp, H., Alem, A., et al. (2017). "Service user involvement in mental health system strengthening in a rural African setting: qualitative study." BMC Psychiatry **17**(1): 187.

> BACKGROUND: It is essential to involve service users in efforts to expand access to mental health care in integrated primary care settings in low- and middle-income countries (LMICs). However, there is little evidence from LMICs to guide this process. The aim of this study was to explore barriers to, and facilitators of, service user/caregiver involvement in rural Ethiopia to inform the development of a scalable approach. METHODS: Thirty nine semi-structured interviews were carried out with purposively selected mental health service users (n = 13), caregivers (n = 10), heads of primary care facilities (n = 8) and policy makers/planners/service developers (n = 8). The interviews were audio-recorded and transcribed in Amharic, and translated into English. Thematic analysis was applied. RESULTS: All groups of participants supported service user and caregiver involvement in mental health system strengthening. Potential benefits were identified as (i) improved appropriateness and quality of services, and (ii) greater protection against mistreatment and promotion of respect for service users. However, hardly any respondents had prior experience of service user involvement. Stigma was considered to be a pervasive barrier, operating within the health system, the local community and individuals. Competing priorities of service users included the need to obtain adequate individual care and to work for survival. Low recognition of the potential contribution of service users seemed linked to limited empowerment and mobilization of service users. Potential health system facilitators included a culture of community oversight of primary care services. All groups of respondents identified a need for awareness-raising and training to equip service users, caregivers, service providers and local community for involvement. Empowerment at the level of individual service users (information about mental health conditions, care and rights) and the group level (for advocacy and representation) were considered essential, alongside improved, accessible mental health care and livelihood interventions. CONCLUSION: As Ethiopia increases access to mental health care, a fundamental barrier to service user involvement is beginning to be addressed. Our study identified further barriers that need to be tackled, including a supportive political climate, and receptiveness amongst stakeholders. The findings will inform the development of a model of service user involvement, which will be piloted and evaluated.

Adams, W. E. (2020). "Unintended consequences of institutionalizing peer support work in mental healthcare." Soc Sci Med **262**: 113249.

> The widespread shift towards recovery-oriented mental healthcare has led to the extensive growth of peer-delivered services. Peer support workers draw on lived experience of mental health challenges and service use to provide non-clinical support services. As peer support services have grown, they have also formalized. This mixed-methods study of peer support work in Pennsylvania (USA) explores how peer support has been institutionalized, and identifies the intended impacts and unintended consequences associated with that process. In Pennsylvania, the inclusion of peer support services as a Medicaid reimbursable service, in addition to county level mandates regarding peer support service availability, have served to institutionalize the

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field. Data include 49 semi-structured interviews conducted with peer support workers (n = 35) and stakeholders (n = 14) in 2016. Qualitative analyses reveal changes to the scope and nature of peer support work, the peer workforce, peer client relationships, and to stigma in the workplace. Despite these changes, peer workers frequently remain underpaid and unable to advance professionally. The institutionalization of peer support serves as a barrier to worker entry and retention and highlights tensions between the consumer-driven origin of the recovery field and the current mental healthcare system. The institutionalization of roles defined by experiential expertise, such as peer support, has the potential to reduce the very centrality of experiential expertise, reproduce social inequalities, and paradoxically impact stigma.

Ahmed, A. O., et al. (2015). "The professional experiences of peer specialists in the Georgia Mental Health Consumer Network." Community Ment Health J **51**(4): 424-436.

There has been an increase in the number of peer-led services within the mental health care system. There however remains little information about the experiences of peers serving in such helping roles. This study explored the professional experiences of peer specialists including the basic roles, benefits, and potential challenges of the peer specialist role. Peer specialists (N = 84) completed a battery of surveys and questionnaires. Qualitative analysis of participants' responses indicated that peer specialists face difficulties such as poor compensation, limited employment opportunities, work stress, emotional stress in helping others, and maintaining personal wellness. Quantitative analyses revealed that recovery attitudes may confer clinical and psychosocial benefits for peer specialists and employment may contribute to hope, empowerment, social engagement, and competence. Peer specialists would benefit from resources and supports aimed at their continued training and supervision. Fostering the vocational advancement of peer specialists could potentially enhance their experiential recovery and community functioning.

Alegría, M., et al. (2008). "Evaluation of a patient activation and empowerment intervention in mental health care." Med Care **46**(3): 247.

Anderson, B. (2007). "Collaborative care and motivational interviewing: improving depression outcomes through patient empowerment interventions." Am J Manag Care **13**(4 Suppl): S103-106.

Patient empowerment interventions have demonstrated significant success in the treatment of several chronic conditions. Recently, 2 such interventions, collaborative care and motivational interviewing, have been employed in the treatment of depression with promise in the managed care setting. Collaborative care initiatives feature a multidisciplinary team of providers to deliver such services as patient education, thorough follow-up, and case management. Motivational interviewing employs specifically tailored dialogue to encourage patients to take an active role in their therapy. Through increased treatment adherence and improved outcomes, these interventions have the potential to decrease the significant overall healthcare costs associated with depression.

Antunes, A., Frasquilho, D., Cardoso, G., et al. (2017). "Perceived effects of the economic recession on population mental health, well-being and provision of care by primary care users and professionals: a qualitative study protocol in Portugal." BMJ Open **7**(9): e017032.

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INTRODUCTION: Economic recession periods can pose accentuated risks to population's mental health and well-being as well as additional threats to health systems. Users and health professionals are key stakeholders in care delivery; however, little attention has been given to their experiences of the crisis. This paper presents a qualitative study protocol to assess users' and health professionals' perceptions about the effects of the post-2008 economic recession on mental health and care delivery in the Lisbon Metropolitan Area, Portugal. METHODS AND ANALYSIS: The methodology to assess perceived effects of the economic recession by primary care users and professionals on population mental health, well-being and provision of care is presented. Focus groups with users and semistructured interviews with health professionals will be carried out in three primary healthcare units in Lisbon areas especially affected by the crisis. Thematic analysis of full-transcribed interviews will be conducted using an iterative and reflexive approach. ETHICS AND DISSEMINATION: The study protocol was approved by the Ethics Committee of NOVA Medical School, NOVA University of Lisbon. The findings will be useful for other researchers and policy-makers to develop and implement the assessment of prevailing experiences of users and health professionals on the effects of the economic recession on mental health and quality of care in primary health context, promoting their involvement and contribution to services responsiveness.

Ariss, J. J., Gerlach, A., Baker, J. B., et al. (2019). "Community-Based Recreation Therapy and Mental Health Recovery: A Mixed-Media Participatory Action Research Study." Prog Community Health Partnersh **13**(2): 161-170.

BACKGROUND: Personal recovery is an individualized process through which people develop a positive identity and live a meaningful life, with symptoms of mental illness. Few studies have explored the role of recreation therapy in the recovery process from the perspectives of individuals with lived experience of mental illness. OBJECTIVES: To understand how community-based recreation therapy can support mental health recovery, from the perspectives of people diagnosed with mental illness, and to guide the development, delivery and evaluation of recovery-oriented mental health services. METHODS: Guided by the principles of participatory action research (PAR) and photovoice, six participant researchers (PRs) generated arts-based media and narrative data in response to the research question: How can therapeutic recreation, in a community mental health center, support the recovery of individuals diagnosed with mental illness? The research group analyzed the qualitative data through a participatory data analysis process. RESULTS: The PRs produced and analyzed 24 pieces of arts-based media and 5 hours of transcribed narrative data describing their artworks' relationship to therapeutic recreation and recovery. The PRs identified seven salient themes through the participatory data analysis process: providing a safe place, promoting hope, finding balance, developing self-wisdom, increasing enjoyment, building confidence, and encouraging self-determination. CONCLUSIONS: Service recipients' unique preferences and perspectives must be integral to service development to deliver therapeutic recreation interventions that are truly recovery-oriented. The research findings will be used to guide the delivery of innovative, collaborative, person-centered programming in community-based mental health settings.

Barbato, A., et al. (2014). "Quality assessment of mental health care by people with severe mental disorders: a participatory research project." Community Ment Health J **50**(4): 402-408.

This study assessed the perceived quality of care by consumers with severe mental disorders. A questionnaire investigating service quality was developed by a consumer focus group and filled

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by 204 consumers. In five areas the negative evaluations exceeded or closely approximated the positive ones: choice of professionals, waiting times, information about illness and medications. All five do not refer to the outcomes of care, but to the concept of responsiveness. The results confirmed that people with severe mental disorders can give value judgments on various aspects of care. However, even in a service strongly oriented towards community care, the consumers' needs in sensitive areas concerning choices, respect and autonomy are not met. The application of the concept of responsiveness to quality improvement may help services to meet consumers' expectations.

Barrett, B., et al. (2010). "Recovery orientation of treatment, consumer empowerment, and satisfaction with services: a mediational model." Psychiatr Rehabil J **34**(2): 153-156.

OBJECTIVE: This study explores the relationship between the recovery orientation of treatment and subjective experiences of consumer empowerment and satisfaction with services for individuals with severe and persistent mental illness. METHODS: Instruments measuring perceptions of empowerment, recovery orientation of treatment, and satisfaction with services were administered to 45 participants enrolled in two demographically similar mental health treatment programs in Tampa, Florida - a community mental health center and an Assertive Community Treatment team. Analyses were conducted according to traditional mediation models. Empowerment was expected to mediate the relationship between the recovery orientation of treatment and consumer satisfaction with services. RESULTS: A recovery-based treatment orientation significantly predicted both consumer empowerment and satisfaction with services. Empowerment mediated the relationship between treatment orientation and consumer satisfaction. CONCLUSIONS: These preliminary findings highlight the impact of the recovery orientation of treatment on empowerment and satisfaction with services among individuals with severe and persistent mental illness.

Baum, F., et al. (2006). "Glossary: Participatory action research." Journal of Epidemiology and Community Health (1979-) **60**(10): 854-857.

Becker, C. B., et al. (2009). "Use of empirically supported interventions for psychopathology: can the participatory approach move us beyond the research-to-practice gap?" Behav Res Ther **47**(4): 265-274.

Dissemination, or distribution, of empirically supported interventions (ESIs) for psychopathology remains a significant challenge. This paper reviews the principles of community-partnership research (CPR) and explores why CPR might improve distribution of psychological ESIs. Benefits of CPR include building trust, pooling resources and knowledge, and better serving a community by directly involving its members in the design and implementation of research. In addition, after establishing a community's trust using CPR, researchers are likely to be better positioned to partner with communities in the further distribution of ESIs via community networks. This paper reviews the case of dissonance-based eating disorder prevention interventions to provide an example of how CPR can facilitate the adoption and distribution of an ESI by a community, in this case, sororities. CPR also presents a number of challenges, however, because it is time consuming and does not always align with funding mechanisms and research designs used in randomized controlled trials. Further, CPR does not necessarily solve the challenge of training providers, though it may help with problem solving. Ultimately, we suggest that the benefits of CPR far outweigh the challenges, and hope that more researchers will adopt these practices so that more individuals can benefit from empirically supported psychological interventions.

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Bengtsson-Tops, A. et Svensson, B. (2010). "Mental health users' experiences of being interviewed by another user in a research project. A qualitative study." J Ment Health **19**(3): 237-242.

> BACKGROUND: Although user involvement in research is an area of high priority there is a lack of knowledge about how users of the mental health system perceive participation in studies carried out by other users. AIM: The aim of the study was to describe how users experience participation in research interviews performed by other users. METHOD: A varied sample of 17 mental health users with experience of being interviewed in a research project by another user was thematically interviewed in this qualitative study. Data was subject to content analysis. RESULTS: Being interviewed by another user was a special experience including both negative and positive aspects, and took place in an atmosphere of comradeship. However, being interviewed by another user could generate feelings of insecurity. This finding indicates requirements from the informants how to perform user-involved research in the future. CONCLUSIONS: In planning for user-involved research education, it is necessary to consider training and issues related to secure ethical principals concerning the informants.

Bergold, J. et Thomas, S. (2012). "Participatory research methods: A methodological approach in motion." Historical Social Research/Historische Sozialforschung: 191-222.

Biegel, D. E., et al. (2010). "A university-agency mental health research collaboration: a case example." Care Manag J **11**(2): 83-90.

> There is significant documentation in the literature of barriers that may prevent research results from being utilized by agencies to inform and impact practice and policy. Such barriers pertain to several factors as follows: (a) those related to the nature of the research enterprise itself (b) those related to differences between the producers and consumers of research, and (c) barriers arising from the differences in organizational contexts of researchers and case management and supported employment agency staff. This article discusses a collaborative relationship between university researchers and agency practitioners in the context of a research project studying the implementation of supported employment, an evidence-based practice. As a case example, it provides an exemplar of the problems and issues of conducting mental health research with community-based agencies and offers strategies and case examples that address these issues.

Blevins, D., et al. (2008). "Evaluating a community-based participatory research project for elderly mental healthcare in rural America." Clin Interv Aging **3**(3): 535-545.

> The purpose of this evaluation was to explore the collaborative nature of partners in a rural mental health program for the elderly, and to test an adapted method of assessing the collaborative process. Sixteen collaborative partners were interviewed to explore ratings of collaboration across 6 domains identified as critical to participatory research. Results indicate that the context of rural Missouri and uniqueness of the program necessitated an approach to collaboration that began with a top-down approach, but greater community responsibility developed over time. Partners recognized the efforts of the program's directors to seek input. Most were satisfied with their roles and the degree of success achieved by the program, although several wanted to have more input in the future in some domains, but not in others. Interviews revealed numerous barriers to achieving sustainability. Methods to improve the assessment of collaboration are discussed and areas for improvement are offered.

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Bonfils, K. A., Luther, L., Fukui, S., et al. (2017). "Correlates of observer-rated active involvement in psychiatric treatment visits." Psychiatry Res **256**: 384-390.

> Among people with serious mental illness, increased patient activation has been linked to a range of key recovery outcomes. To date, patient activation has been measured largely through self-report. The present study investigated correlates of a new tool that assesses active involvement through rating audio-recordings of treatment visits. The key domains of patient activation assessed in visits included: patients asking questions, discussing with providers instances of being active in managing illness outside the session, talking about goals, bringing up concerns, making evaluative statements about treatment, setting the agenda for the visit, and making requests about the course of treatment. The new coding scheme proved to be a feasible and reliable method for identifying multi-faceted behavioral indicators of patient activation. Contrary to our hypotheses, in a sample of 166 people diagnosed with severe mental illnesses, self-reported activation and observer-rated indices of activation were often not correlated or correlated in unexpected directions with the new behavioral measure of patient activation. This suggests the nature of patient activation may be complex and work is needed to understand how observer-rated and self-rated activation may predict differential recovery outcomes.

Boote, J., et al. (2002). "Consumer involvement in health research: a review and research agenda." Health policy **61**(2): 213-236.

Boudreaux, E. D., et al. (2009). "The Psychiatric Emergency Research Collaboration-01: methods and results." Gen Hosp Psychiatry **31**(6): 515-522.

> OBJECTIVE: To describe the Psychiatric Emergency Research Collaboration (PERC), the methods used to create a structured chart review tool and the results of our multicenter study. METHOD: Members of the PERC Steering Committee created a structured chart review tool designed to provide a comprehensive picture of the assessment and management of psychiatric emergency patients. Ten primary indicators were chosen based on the Steering Committee's professional experience, the published literature and existing consensus panel guidelines. Eight emergency departments completed data abstraction of 50 randomly selected emergency psychiatric patients, with seven providing data from two independent raters. Inter-rater reliability (Kappas) and descriptive statistics were computed. RESULTS: Four hundred patient charts were abstracted. Initial concordance between raters was variable, with some sites achieving high agreement and others not. Reconciliation of discordant ratings through re-review of the original source documentation was necessary for four of the sites. Two hundred eighty-five (71%) subjects had some form of laboratory test performed, including 212 (53%) who had urine toxicology screening and 163 (41%) who had blood alcohol levels drawn. Agitation was present in 220 (52%), with 98 (25%) receiving a medication to reduce agitation and 22 (6%) being physically restrained. Self-harm ideation was present in 226 (55%), while other-harm ideation was present in 82 (20%). One hundred seventy-nine (45%) were admitted to an inpatient or observation unit. CONCLUSION: Creating a common standard for documenting, abstracting and reporting on the nature and management of psychiatric emergencies is feasible across a wide range of health care institutions.

Brekke, J. S., et al. (2007). "Translational science at the National Institute of Mental Health: Can social work take its rightful place?" Research on Social Work Practice **17**(1): 123-133.

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Brett, J., et al. (2014). "Mapping the impact of patient and public involvement on health and social care research: a systematic review." Health Expectations **17**(5): 637-650.

Broer, T., et al. (2010). "Opening the black box of quality improvement collaboratives: an Actor-Network theory approach." BMC Health Serv Res **10**: 265.

> BACKGROUND: Quality improvement collaboratives are often labeled as black boxes because effect studies usually do not describe exactly how the results were obtained. In this article we propose a way of opening such a black box, by taking up a dynamic perspective based on Actor-Network Theory. We thereby analyze how the problematisation process and the measurement practices are constructed. Findings from this analysis may have consequences for future evaluation studies of collaboratives. METHODS: In an ethnographic design we probed two projects within a larger quality improvement collaborative on long term mental health care and care for the intellectually disabled. Ethnographic observations were made at nine national conferences. Furthermore we conducted six case studies involving participating teams. Additionally, we interviewed the two program leaders of the overall projects. RESULTS: In one project the problematisation seemed to undergo a shift of focus away from the one suggested by the project leaders. In the other we observed multiple roles of the measurement instrument used. The instrument did not only measure effects of the improvement actions but also changed these actions and affected the actors involved. CONCLUSIONS: Effectiveness statistics ideally should be complemented with an analysis of the construction of the collaborative and the improvement practices. Effect studies of collaboratives could benefit from a mixed methods research design that combines quantitative and qualitative methods.

Brown, C. H., et al. (2012). "Partnerships for the design, conduct, and analysis of effectiveness, and implementation research: experiences of the prevention science and methodology group." Adm Policy Ment Health **39**(4): 301-316.

> What progress prevention research has made comes through strategic partnerships with communities and institutions that host this research, as well as professional and practice networks that facilitate the diffusion of knowledge about prevention. We discuss partnership issues related to the design, analysis, and implementation of prevention research and especially how rigorous designs, including random assignment, get resolved through a partnership between community stakeholders, institutions, and researchers. These partnerships shape not only study design, but they determine the data that can be collected and how results and new methods are disseminated. We also examine a second type of partnership to improve the implementation of effective prevention programs into practice. We draw on social networks to studying partnership formation and function. The experience of the Prevention Science and Methodology Group, which itself is a networked partnership between scientists and methodologists, is highlighted.

Bumbarger, B. K. et Campbell, E. M. (2012). "A state agency-university partnership for translational research and the dissemination of evidence-based prevention and intervention." Adm Policy Ment Health **39**(4): 268-277.

> This article describes a decade-long partnership between the Prevention Research Center at Penn State and the Pennsylvania Commission on Crime and Delinquency. This partnership has

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evolved into a multi-agency initiative supporting the implementation of nearly 200 replications of evidence-based prevention and intervention programs, and a series of studies indicating a significant and sustained impact on youth outcomes and more efficient utilization of system resources. We describe how the collaboration has developed into a sophisticated prevention support infrastructure, discuss the partnership and policy lessons learned throughout this journey, and identify remaining issues in promoting this type of research-policy partnership.

Burke, E., Pyle, M., Machin, K., et al. (2019). "The effects of peer support on empowerment, self-efficacy, and internalized stigma: A narrative synthesis and meta-analysis." Stigma and Health **4**(3): 337-356.

Peer support is sometimes formalized and offered as an intervention in mental health services and organizations. Evidence suggests that empowerment, self-efficacy, and internalized stigma are theoretically linked and implicated in the change processes involved in peer support. This review aimed to synthesize quantitative evidence published in the English language from trials that introduced any type of peer support intervention on the outcomes of empowerment, self-efficacy, and internalized stigma for those in receipt of peer support. Literature searches were conducted between November 2016 and April 2017 on CENTRAL, CINAHL, Clinicaltrials.gov, EMBASE, MEDLINE, PsycINFO, and Web of Science databases. Study quality was appraised. Results were integrated first through narrative synthesis. Where data was available, effect sizes were calculated and meta-analyses conducted when there were at least four randomized trials with similar characteristics. Twenty-three studies met inclusion criteria and could be separated into three broad categories: peer-led group interventions, one-to-one peer support, and peer-run services. Most were moderate to weak in quality. Meta-analyses were conducted for group interventions only. Results suggested that peer-facilitated time-limited group interventions can result in small but significant improvements in empowerment and self-efficacy compared with treatment as usual. Evidence was inconclusive for one-to-one peer support, peer-run services, and for internalized stigma. Areas for future research include: equivalence trials of group interventions with nonpeer facilitators, developing peer-led group interventions specific to the needs of people with particular mental health difficulties, high-quality research on one-to-one peer support and peer-run services, and research to understand the essential components and change mechanisms involved in peer support. (PsycINFO Database Record (c) 2019 APA, all rights reserved)

Callander, R., et al. (2011). "Consumers and carers as partners in mental health research: reflections on the experience of two project teams in Victoria, Australia." Int J Ment Health Nurs **20**(4): 263-273.

A successful working partnership in research between a consumer project team from the Victorian Mental Illness Awareness Council and a carer project team from the Victorian Mental Health Carers Network was forged during their collaborative involvement in an innovative 2-year pilot project funded by the Victorian Government of Australia. This project trialled new ways of capturing consumer and carer experiences of mental health services, and that feedback was integrated into service quality improvement. Towards the end of the project, an external facilitator was used to enable the two teams to reflect on their experience of working together so that their joint story could be shared with others and used to promote further use of this approach in the mental health field. Main findings included the importance of having strong support and belief at leadership levels, opportunities to build the relationship and develop mutual trust and respect, a common vision and a clearly articulated set of values, targeted training appropriate to the needs of the team members, independent work bases, and mutual

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support to overcome challenges encountered during the project. The experience forged a close working relationship between the two teams and has set the scene for further participation of consumers and carers in research and innovative quality-improvement processes in the mental health field.

Camar, O. (2015). "Community-Based Participatory Action Research in Mental Health: A Special Focus on PhotovoiceOzge Carta." European Journal of Public Health **25**(suppl_3): ckv169.056-ckv169.056. http://dx.doi.org/10.1093/eurpub/ckv169.056

> The presentation provides an overview of CBPAR approach and a more detailed description of the photo-voice methodology, in addition to several examples of photo-voice menta l health studies from around the world.

Castonguay, L. G., et al. (2010). "Helpful and hindering events in psychotherapy: a practice research network study." Psychotherapy (Chic) **47**(3): 327-344.

> This paper presents the findings of a psychotherapy process study conducted within the Pennsylvania Psychological Association Practice Research Network (PPA-PRN). The investigation was the product of a long-term collaborative effort, both in terms of the study design and implementation, between experienced clinicians of various theoretical orientations and full-time psychotherapy researchers. Based on a relatively large sample of clients seen in independent practice settings, close to 1,500 therapeutic events (described by clients and therapists as being particularly helpful or hindering) were collected. These events were coded by three independent observers using a therapy content analysis system. Among the findings, both clients and therapists perceived the fostering of self-awareness as being particularly helpful. The results also point to the importance of paying careful attention to the therapeutic alliance and other significant interpersonal relationships. The merits and difficulties of conducting scientifically rigorous and clinically relevant studies in naturalistic contexts are also discussed.

Chambers, M., McAndrew, S., Nolan, F., et al. (2017). "Service user involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire." Health Expect **20**(5): 871-877.

> Service users' involvement in mental health service research is increasingly acknowledged as important, yet, whilst involving users of mental health services as research participants is commonplace, seeking out their experience and indeed their "expertise" to facilitate the development of tools to be used within mental health services is in its infancy. This article describes the involvement and views of service users in the development of a nursing metric-the Therapeutic Engagement Questionnaire. It presents their role in the three stages of development: generation, statement reduction and authentication.

Charles, A., Thompson, D., Nixdorf, R., et al. (2020). "Typology of modifications to peer support work for adults with mental health problems: systematic review." Br J Psychiatry **216**(6): 301-307.

> BACKGROUND: Peer support work roles are being implemented internationally, and increasingly in lower-resource settings. However, there is no framework to inform what types of modifications are needed to address local contextual and cultural aspects. AIMS: To conduct a systematic review identifying a typology of modifications to peer support work for adults with

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mental health problems. METHOD: We systematically reviewed the peer support literature following PRISMA guidelines for systematic reviews (registered on PROSPERO (International Prospective Register of Systematic Reviews) on 24 July 2018: CRD42018094832). All study designs were eligible and studies were selected according to the stated eligibility criteria and analysed with standardised critical appraisal tools. A narrative synthesis was conducted to identify types of, and rationales for modifications. RESULTS: A total of 15 300 unique studies were identified, from which 39 studies were included with only one from a low-resource setting. Six types of modifications were identified: role expectations; initial training; type of contact; role extension; workplace support for peer support workers; and recruitment. Five rationales for modifications were identified: to provide best possible peer support; to best meet service user needs; to meet organisational needs, to maximise role clarity; and to address socioeconomic issues. CONCLUSIONS: Peer support work is modified in both pre-planned and unplanned ways when implemented. Considering each identified modification as a candidate change will lead to a more systematic consideration of whether and how to modify peer support in different settings. Future evaluative research of modifiable versus non-modifiable components of peer support work is needed to understand the modifications needed for implementation among different mental health systems and cultural settings.

Chatterjee, S., et al. (2011). "Collaborative community based care for people and their families living with schizophrenia in India: protocol for a randomised controlled trial." Trials **12**: 12.

BACKGROUND: There is a large treatment gap with few community services for people with schizophrenia in low income countries largely due to the shortage of specialist mental healthcare human resources. Community based rehabilitation (CBR), involving lay health workers, has been shown to be feasible, acceptable and more effective than routine care for people with schizophrenia in observational studies. The aim of this study is to evaluate whether a lay health worker led, Collaborative Community Based Care (CCBC) intervention, combined with usual Facility Based Care (FBC), is superior to FBC alone in improving outcomes for people with schizophrenia and their caregivers in India. METHODS/DESIGN: This trial is a multi-site, parallel group randomised controlled trial design in India.The trial will be conducted concurrently at three sites in India where persons with schizophrenia will be screened for eligibility and recruited after providing informed consent. Trial participants will be randomly allocated in a 2:1 ratio to the CCBC+FBC and FBC arms respectively using an allocation sequence pre-prepared through the use of permuted blocks, stratified within site. The structured CCBC intervention will be delivered by trained lay community health workers (CHWs) working together with the treating Psychiatrist. We aim to recruit 282 persons with schizophrenia. The primary outcomes are reduction in severity of symptoms of schizophrenia and disability at 12 months. The study will be conducted according to good ethical practice, data analysis and reporting guidelines. DISCUSSION: If the additional CCBC intervention delivered by front line CHWs is demonstrated to be effective and cost-effective in comparison to usually available care, this intervention can be scaled up to expand coverage and improve outcomes for persons with schizophrenia and their caregivers in low income countries. TRIAL REGISTRATION: The trial is registered with the International Society for the Registration of Clinical Trials and the allocated unique ID number is ISRCTN 56877013.

Cheng, P., Xia, G., Pang, P., et al. (2020). "COVID-19 Epidemic Peer Support and Crisis Intervention Via Social Media." Community Ment Health J **56**(5): 786-792.

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This article describes a peer support project developed and carried out by a group of experienced mental health professionals, organized to offer peer psychological support from overseas to healthcare professionals on the frontline of the COVID-19 outbreak in Wuhan, China. This pandemic extremely challenged the existing health care systems and caused severe mental distress to frontline healthcare workers. The authors describe the infrastructure of the team and a novel model of peer support and crisis intervention that utilized a popular social media application on smartphone. Such a model for intervention that can be used elsewhere in the face of current global pandemic, or future disaster response.

Chien, W. T., Clifton, A. V., Zhao, S., et al. (2019). "Peer support for people with schizophrenia or other serious mental illness." Cochrane Database Syst Rev **4**(4): Cd010880.

BACKGROUND: Peer support provides the opportunity for peers with experiential knowledge of a mental illness to give emotional, appraisal and informational assistance to current service users, and is becoming an important recovery-oriented approach in healthcare for people with mental illness. OBJECTIVES: To assess the effects of peer-support interventions for people with schizophrenia or other serious mental disorders, compared to standard care or other supportive or psychosocial interventions not from peers. SEARCH METHODS: We searched the Cochrane Schizophrenia Group's Study-Based Register of Trials on 27 July 2016 and 4 July 2017. There were no limitations regarding language, date, document type or publication status. SELECTION CRITERIA: We selected all randomised controlled clinical studies involving people diagnosed with schizophrenia or other related serious mental illness that compared peer support to standard care or other psychosocial interventions and that did not involve 'peer' individual/group(s). We included studies that met our inclusion criteria and reported useable data. Our primary outcomes were service use and global state (relapse). DATA COLLECTION AND ANALYSIS: The authors of this review complied with the Cochrane recommended standard of conduct for data screening and collection. Two review authors independently screened the studies, extracted data and assessed the risk of bias of the included studies. Any disagreement was resolved by discussion until the authors reached a consensus. We calculated the risk ratio (RR) and 95% confidence interval (CI) for binary data, and the mean difference and its 95% CI for continuous data. We used a random-effects model for analyses. We assessed the quality of evidence and created a 'Summary of findings' table using the GRADE approach. MAIN RESULTS: This review included 13 studies with 2479 participants. All included studies compared peer support in addition to standard care with standard care alone. We had significant concern regarding risk of bias of included studies as over half had an unclear risk of bias for the majority of the risk domains (i.e. random sequence generation, allocation concealment, blinding, attrition and selective reporting). Additional concerns regarding blinding of participants and outcome assessment, attrition and selective reporting were especially serious, as about a quarter of the included studies were at high risk of bias for these domains.All included studies provided useable data for analyses but only two trials provided useable data for two of our main outcomes of interest, and there were no data for one of our primary outcomes, relapse. Peer support appeared to have little or no effect on hospital admission at medium term (RR 0.44, 95% CI 0.11 to 1.75; participants = 19; studies = 1, very low-quality evidence) or all-cause death in the long term (RR 1.52, 95% CI 0.43 to 5.31; participants = 555; studies = 1, very low-quality evidence). There were no useable data for our other prespecified important outcomes: days in hospital, clinically important change in global state (improvement), clinically important change in quality of life for peer supporter and service user, or increased cost to society.One trial compared peer support with clinician-led support but did not report any useable data for the

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above main outcomes. AUTHORS' CONCLUSIONS: Currently, very limited data are available for the effects of peer support for people with schizophrenia. The risk of bias within trials is of concern and we were unable to use the majority of data reported in the included trials. In addition, the few that were available, were of very low quality. The current body of evidence is insufficient to either refute or support the use of peer-support interventions for people with schizophrenia and other mental illness.

Chou, K. R., et al. (2012). "Psychosocial rehabilitation activities, empowerment, and quality of community-based life for people with schizophrenia." Arch Psychiatr Nurs **26**(4): 285-294.

Many variables influencing quality of life (QOL) for outpatients with schizophrenia have been identified from prior studies. Symptom severity, psychosocial rehabilitation activities, and empowerment have all been clearly identified as key variables. However, which variables are the most influential and important factors remains unknown; factors influencing QOL, either directly or indirectly and to what degree, need to be examined. The aim of this study was to test the hypothesis that empowerment is a possible mediator of how (a) psychiatric symptoms and (b) psychosocial rehabilitation activities affect QOL for outpatients with schizophrenia in the community. We used the probability proportional to size random sampling for 190 outpatients with schizophrenia at 10 community rehabilitation centers in Taipei, such that samples consisted of adults who fulfilled the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition criteria. The instruments included the questionnaire to gather demographic and disease information, the Empowerment Scale, the Psychiatric Symptoms Scale, the psychosocial rehabilitation activity (PRA), and the Quality of Life Scale for Psychiatric Patients. Beyond descriptive statistics, correlation and structural equation models were computed. Findings showed that empowerment in outpatients with schizophrenia mediates QOL, whereas psychosocial rehabilitation activities seem to increase empowerment, which may in turn increase QOL. Psychotic symptoms seem to have a direct effect of decreasing QOL that could not be mediated by empowerment. Empowerment had a significant effect on QOL for outpatients with schizophrenia. The findings of this study support the importance of empowerment and rehabilitation activities for promoting QOL among community outpatients. We suggest that various rehabilitation programs and empowerment health education are needed to enhance QOL for schizophrenia outpatients in the community.

Citrome, L., et al. (2008). "Public-academic partnerships: integrating state psychiatric hospital treatment and clinical research." Psychiatr Serv **59**(9): 958-960.

Collaboration between state clinical treatment services and academic research is fertile ground for clinical research opportunities. Such joint initiatives require careful planning, including provisions for joint training, integration of research staff into clinical activities, and integration of clinical treatment staff into research activities. The authors describe the planning and development of a 24-bed research unit at the Nathan S. Kline Institute for Psychiatric Research, colocated on the same campus as Rockland Psychiatric Center, each of which is an independent facility operated by the New York State Office of Mental Health.

Clarke, R., et al. (2015). "What's in it for me? The meaning of involvement in a self-advocacy group for six people with intellectual disabilities." J Intellect Disabil **19**(3): 230-250.

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BACKGROUND: This article explores the experiences of six people with intellectual disabilities in the context of a self-advocacy group, identifying the benefits and difficulties of being part of the group. MATERIALS AND METHODS: Six adults with intellectual disabilities were interviewed about their experiences. Each individual took part in two individual and two group interviews. The transcripts were analysed using thematic analysis. RESULTS: Analysis revealed four themes, namely, being part of the group, self-esteem, self-determination and empowerment. CONCLUSION: Being part of the group is central to the experience of self-esteem, self-development and empowerment. Responses allow the exploration of the interrelationship between individual, group and community. Consideration is given to models of disability and the evidence base in relation to personal and political outcomes of self-advocacy. Links are made with developing a sense of self, self-determination, interpersonal learning and building resilience. Implications for practice are discussed.

Clements, K. (2012). "Participatory action research and photovoice in a psychiatric nursing/clubhouse collaboration exploring recovery narrative." J Psychiatr Ment Health Nurs **19**(9): 785-791.

The Clubhouse of Winnipeg (a community psychosocial rehabilitation centre) collaborated with a psychiatric nursing assistant professor on a participatory action research (PAR) project exploring the concept of recovery using a using a research method called photovoice. The collaborative project -Our Photos Our Voices- demonstrates how PAR and photovoice are well suited for collaborative research in mental health which honours principles underlying consumer empowerment and recovery. The foundation of empowerment is the power to act on one's behalf; PAR and photovoice support the full participation of concerned individuals in all aspects of research with the ultimate goal of action to solve problems or to meet goals identified by those individuals. Empowerment is also the ability to lay claim to one's own truth. At the core of the recovery model is the principle that recovery is defined by the individual and based on individual determinations of meaningful goals and a meaningful life. The Our Photos Our Voices project uses PAR and photovoice to effectively access, explore, document and share personal, local knowledge about recovery grounded in the personal experience of the Clubhouse researchers.

Cook, J. A., et al. (2010). "Participatory action research to establish self-directed care for mental health recovery in Texas." Psychiatr Rehabil J **34**(2): 137-144.

OBJECTIVE: This article describes a public-academic collaboration between a university research center and the Texas state mental health authority to design and evaluate a unique "money follows the person" model called self-directed care (SDC). SDC programs give participants control over public funds to purchase services and supports for their own recovery. METHODS: Through a participatory action research process, the project combined use of evidence-based practice and community consensus as a tool for system change. RESULTS: The story of this effort and the program that resulted are described, along with quantitative and qualitative data from the project's start-up phase. CONCLUSIONS: Lessons learned about the importance of community collaboration are discussed in light of the current emphasis on public mental health system transformation through alternative financing mechanisms.

Cook, J. R. et Kilmer, R. P. (2012). "Systems of care: new partnerships for community psychology." Am J Community Psychol **49**(3-4): 393-403.

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For almost two decades, the federal government has supported the development of integrated models of mental health service delivery for children and families, known as systems of care (SOCs), that strive to be child-centered, family-focused, community-based, and culturally competent. These efforts align well with the values and principles (e.g., empowerment, collaboration, strengths emphasis, focus on macro-level social/system change) central to community psychology (CP; Kloos et al. in Community psychology, Cengage Learning, Belmont, 2012). Despite the convergence of many core values, CPs have historically been underrepresented in key roles in SOC initiatives. However, this has changed in recent years, with increasing examples of community psychology skills and principles applied to the development, implementation, and evaluation of SOCs. Because successful and sustainable implementation of SOCs requires community and system-level change, and SOCs are increasingly being urged to adopt a stronger "public health" orientation (Miles et al. in A public health approach to children's mental health: a conceptual framework, Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children's Mental Health, Washington, DC, 2010), there is great potential for CPs to play important roles in SOCs. This paper discusses opportunities and roles for CPs in SOCs in applied research and evaluation, community practice, and training.

Cortes, D. E., et al. (2009). "Patient--provider communication: understanding the role of patient activation for Latinos in mental health treatment." Health Educ Behav **36**(1): 138-154.

This article highlights results from the Right Question Project-Mental Health (RQP-MH), an intervention designed to teach skills in question formulation and to increase patients' participation in decisions about mental health treatment. Of participants in the RQP-MH intervention, 83% were from a Latino background, and 75% of the interviews were conducted in Spanish. The authors present the steps participants undertook in the process of becoming "activated" to formulate effective questions and develop decision-making skills in relation to their care. Findings suggest that patient activation and empowerment are interdependent because many of the skills (i.e., question formulation, direct patient-provider communication) required to become an "activated patient" are essential to achieve empowerment. Also, findings suggest that cultural and contextual factors can influence the experience of Latinos regarding participation in health care interactions. The authors provide recommendations for continued research on the patient activation process and further application of this strategy in the mental health field, especially with Latinos.

Cosh, S., Zenter, N., Ay, E. S., et al. (2017). "Clinical Decision Making and Mental Health Service Use Among Persons With Severe Mental Illness Across Europe." Psychiatr Serv **68**(9): 970-974.

OBJECTIVE: The study explored relationships between preferences for and experiences of clinical decision making (CDM) with service use among persons with severe mental illness. METHODS: Data from a prospective observational study in six European countries were examined. Associations of baseline staff-rated (N=213) and patient-rated (N=588) preferred and experienced decision making with service use were examined at baseline by using binomial regressions and at 12-month follow-up by using multilevel models. RESULTS: A preference by patients and staff for active patient involvement in decision making, rather than shared or passive decision making, was associated with longer hospital admissions and higher costs at baseline and with increases in admissions over 12 months (p=.043). Low patient-rated satisfaction with an experienced clinical decision was also related to increased costs over the

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study period (p=.005). CONCLUSIONS: A preference for shared decision making may reduce health care costs by reducing inpatient admissions. Patient satisfaction with decisions was a predictor of costs, and clinicians should maximize patient satisfaction

Crawford, M. J., et al. (2003). "User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers." Acta Psychiatr Scand **107**(6): 410-414.

OBJECTIVE: To identify methods for involving service users in the planning and delivery of psychiatric services and factors which may assist and impede this process. METHOD: A cross-sectional postal survey of user groups and providers of psychiatric services throughout Greater London (UK). RESULTS: Seventeen (94%) service providers and 29 (48%) user groups responded to the survey. Service providers employed a wide variety of different methods for involving users but none met national standards for user involvement (UI). Service providers stated that the main obstacle to UI was that users who took part were not representative of local patients. User groups highlighted staff resistance as a major obstacle and 80% stated that they were not satisfied with current arrangements for UI. CONCLUSION: While users and providers of mental health services were able to identify changes resulting from UI the responsiveness of staff and the representativeness of service users may be impeding this process.

Crepaz-Keay, D. (2016). "Empowering mental health service users and their family carers. Practical examples from the United Kingdom." L'information psychiatrique **92**(9): 722.
http://www.cairn.info/revue-l-information-psychiatrique-2016-9-page-718.htm

Cet article va traiter de l'autonomisation des personnes qui utilisent les services ayant trait à la santé mentale, et de l'entourage qui les prend en charge. Il décrira les différents niveaux auxquels l'autonomisation peut avoir lieu en s'appuyant sur les travaux de l'Organisation mondiale de la santé, et sur les directives politiques et pratiques ayant cours au Royaume-Uni. Cet article va donc exposer en détail, et en pratique, deux exemples d'autonomisation. Le premier est focalisé sur un niveau structurel et stratégique, avec le développement d'un forum national pour la santé mentale au Pays de Galles. Le second concerne un niveau individuel, le développement et la prestation d'interventions d'auto-gestion et de soutien par des pairs pour des utilisateurs de services de santé mentale. L'article explorera les avantages de l'autonomisation des personnes directement concernées, et de façon plus large, de la communauté pouvant y avoir recours.

Cuijpers, P., et al. (2010). "Recruiting participants for interventions to prevent the onset of depressive disorders: possible ways to increase participation rates." BMC Health Serv Res **10**: 181.

BACKGROUND: Although indicated prevention of depression is available for about 80% of the Dutch population at little or no cost, only a small proportion of those with subthreshold depression make use of these services. METHODS: A narrative review is conducted of the Dutch preventive services in mental health care, also addressing the problem of low participation rates. We describe possible causes of these low participation rates, which may be related to the participants themselves, the service system, and the communication to the public, and we put forward possible solutions to this problem. RESULTS: There are three main groups of reasons why the participation rates are low: reasons within the participants (e.g., not considering themselves as being at risk; thinking the interventions are not effective; or being unwilling to participate because of the stigma associated with depression); reasons within the health care

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system; and reasons associated with the communication about the preventive services. Possible solutions to increasing the participation rate include organizing mass media campaigns, developing internet-based preventive interventions, adapting preventive interventions to the needs of specific subpopulations, positioning the services in primary care, integrating the interventions in community-wide interventions, and systematically screening high-risk groups for potential participants. DISCUSSION: Prevention could play an important role in public mental health in reducing the enormous burden of depression. However, before this can be realized more research is needed to explore why participation rates are low and how these rates can be improved.

Davidson, L., et al. (2010). ""I don't know how to find my way in the world": contributions of user-led research to transforming mental health practice." Psychiatry **73**(2): 101-113.

BACKGROUND: A number of forces have converged to promote participatory research in mental health. AIM: To present the findings of a user-led project in which eight people in recovery conducted narrative interviews with 80 peers. METHOD: Interviews focused on what participants' lives were like, what they would like their lives to be like, the role of mental health services, and how they would choose to spend their mental health dollars. Researchers used qualitative analysis to identify key themes from the first 30 interviews. RESULTS: Participants described multiple, profound losses and feeling that they were existing day-to-day, with their symptoms under control but not knowing how to make their way in the world. They suggested it would be useful to have a "map" to guide them back to a normal life, and reported that mental health care was most useful when it attended both to controlling illness and enabling them to rebuild an ordinary life. If they had the choice, they would spend their mental health dollars at this point primarily on having other people act as guides in pursuit of normal activities that interest them. CONCLUSION: Mental health care can be more effective in helping people join in to normal activities.

De Barros, M. M., et al. (2009). "[Knowledge and practices of the community health agent in the universe of mental disorder]." Cien Saude Colet **14**(1): 227-232.

This qualitative investigation aimed at collecting information about the knowledge and practices of the community health agents related to the universe of mental disorders. Fourteen agents working in the Family Health Program in Sobral, Ceara were interviewed. We deduced that the concepts of mental disorder are constructed in a process influenced by subjective and socio-cultural aspects and in connection with concrete experiences. The community health agents judge mentally disturbed persons on the basis of different criteria such as normal or abnormal behavior standards and the capacity to make judgments. Social isolation emerged as an important factor, considered by the different research subjects as the cause, the consequence and even as the mental disorder itself. Fear, as a consequence of the strange behavior of people with mental disorders, was identified as an important obstacle for the performance of the community health agents. The strategies adopted by these professionals, fundamentally based on dialogue, reveal concern with social inclusion and the need to involve the families in the care of people with mental disorders.

Dearman, S. P., Joiner, A. B., Gordon, M., et al. (2018). "Experiences of Patients with Mental Illness' Interactions with Medical Students: A Systematic Review." Can J Psychiatry **63**(1): 4-11.

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OBJECTIVES: Mental health is a key area for learning within undergraduate medical education. Given the nature of mental illness, interactions may have the potential to uniquely affect patients. This study set out to systematically review studies reporting experiences and perceptions of patients with mental illness' clinical interactions with medical students. This includes which factors encourage patients to interact with medical students and if patients perceive negative and positive effects from these interactions. METHOD: Studies reporting patient experiences of involvement in undergraduate medicine were included. A standardised search of online databases was carried out independently by 2 authors and consensus reached on the inclusion of studies. Data extraction and quality assessment were also completed independently, after which a content analysis of interventions was conducted and key themes extracted. Studies were included from peer-reviewed journals, in any language. RESULTS: Eight studies from 5 countries were included, totaling 1088 patients. Most patients regarded interacting with medical students as a positive experience. Patients described feeling comfortable with medical students, and the majority believed it is important for students to 'see real patients'. Patients described benefits to them as enjoyment, being involved in student education, and developing an illness narrative. CONCLUSIONS: Results suggest that most patients with mental illness want to interact with medical students, and this should be encouraged during student placements. Further research, however, is required to understand in more depth what else can be done to improve the comfort and willingness for patients to interact with students, including barriers to this.

Debyser, B., Grypdonck, M. H., Defloor, T., et al. (2011). "Involvement of inpatient mental health clients in the practical training and assessment of mental health nursing students: Can it benefit clients and students?" Nurse Educ Today **31**(2): 198-203.

Even though the central position of the client has been recognized in psychiatric nursing education, the client is seldom formally involved in the feedback provided to students during practical training. This research paper focuses on three questions: (1) What conditions support the gathering of meaningful client feedback to enhance the student's learning process and client's wellbeing? (2) Does the use of the practical model for client feedback lead to positive experiences, and if so, under what conditions? (3) To what extent is a client's feedback on the student's work performance, consistent with feedback from the mentor (nurse from the ward), the teacher and the student? Based on a literature review, participatory observation and contacts with experts, a practical model was developed to elicit client feedback. Using this model in two psychiatric inpatient services, clients were actively and formally involved in providing feedback to four, final year psychiatric nursing students. Clients, nurses, teachers and students were interviewed and data were analysed using a qualitative explorative research approach. Analyses revealed that client feedback becomes meaningful in a safe environment created by the psychiatric nurse. Client feedback generates a learning effect for the student and supports the student's recognition of the value and vulnerability

Deering, K., Pawson, C., Summers, N., et al. (2019). "Patient perspectives of helpful risk management practices within mental health services. A mixed studies systematic review of primary research." J Psychiatr Ment Health Nurs **26**(5-6): 185-197.

WHAT IS KNOWN ABOUT THE SUBJECT?: Risk in psychiatry involves harm to self or others owing to mental health difficulties, for example iatrogenic effects of treatment, self-harm, suicide and violence. Risk management is a framework to minimize risks, comprising of risk assessment,

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generation of risk management plans and evaluation of interventions. Literature has extensively explored risk management and presented a critique that its practices can lead to patient harm. However, there is a paucity of literature about what patients identify as helpful risk management practices, despite the potential for such patient views to ameliorate harm and improve mental health care. WHAT THIS PAPER ADDS TO EXISTING KNOWLEDGE: Interpersonal relationships with clinicians, and communication that keeps patients involved and informed of management processes, were found to be central to beneficial risk management practices, while patients having agency and autonomy to influence their participation was also important. Beneficial interpersonal relationships and connectivity in the form of patients' wider community of support were found to be influential in aiding risk management. Meaningful relationships, and particularly peer support, that maintained personal and collective identities were prevalent in the literature. WHAT ARE THE IMPLICATIONS FOR PRACTICE?: Rendering risk management more visible and accessible in practice might cultivate an openness that promotes patient participation. This includes drawing on a wider network of support, for example the patient's friends and family, as well as having advocacy utilizing peer support. Abstract Introduction Minimizing the harm that patients pose to themselves and others, due to mental health difficulties, is a central component of risk management in psychiatry. However, risk management itself can cause patient harm, but despite this and the potentially informative value of lived experience, little is known about what patients want or expect from risk management. Aim To review research and explore what patients consider beneficial in risk management practice. Method A mixed studies systematic review utilizing PRISMA guidelines, alongside a convergent qualitative design to categorize findings. Results Twelve papers were identified, generating two categories of beneficial practices: interpersonal relationships and communication with clinicians; coupled with patient agency in their own risk management. Discussion Connectivity appears important. Particularly patients feeling involved, and their voices being heard in both the identification of risks and then shaping risk management practice. Moreover, this included involvement of friends, family and peers to widen input and supportive networks beyond clinical relationships. Implications for Practice Risk management needs to be an accessible part of care, which is more inclusive of patient views and needs. The latter might also be aided by drawing on the patient's wider community in order to provide more effective support and risk management.

Delman, J. (2012). "Participatory action research and young adults with psychiatric disabilities." Psychiatr Rehabil J **35**(3): 231-234.
https://www.ncbi.nlm.nih.gov/pubmed/22246121

TOPIC: Participatory Action Research (PAR) methods are increasingly being used to include people with psychiatric disabilities in the research production process. PAR places a strong emphasis on collaboration between academic researchers and the disadvantaged community, along with strategies for overcoming barriers to collaboration. PURPOSE: The author describes key principles for engaging young adults with psychiatric disabilities as research associates in a participatory action research (PAR) project. SOURCES USED: Over the past decade, the author developed substantial knowledge by leading or co-leading five (5) funded PAR projects with young adults with psychiatric disabilities and has integrated this experience with an analysis of relevant publications. CONCLUSIONS AND IMPLICATIONS FOR PRACTICE: The key components for achieving successful PAR with young adult researchers align well with the literature on PAR with adults with psychiatric disabilities. Specific adaptations for transition age youth researchers

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include mentorship from more experienced researchers and the availability of specialized vocational supports.

Djellouli, N., Jones, L., Barratt, H., et al. (2019). "Involving the public in decision-making about large-scale changes to health services: A scoping review." Health policy **123**(7): 635-645.
http://www.sciencedirect.com/science/article/pii/S0168851019301137

> Background Public involvement in large-scale changes (LSC) to health services is strongly promoted – and even mandated – in several health systems. This scoping review aimed to describe the evidence about how public involvement is conceptualised and conducted in LSC, with what impact, and how different stakeholders perceived this process. Methods After searching eight databases, 34 publications were included. Data were extracted and charted using a standardised form. Findings from the literature were discussed with frontline stakeholders. Results Public involvement remains poorly defined and its aims lack clarity in LSC. Public meetings are most often used to gather public views but raise the issue of representativeness. However, evidence in the literature is scarce about which involvement methods – informative and deliberative – are appropriate for the different stages of the LSC and with what impact. In several cases, the involved public felt they had no influence on decision-making regarding LSC proposals, sometimes leading to an environment of mistrust. In those instances, the public understood the technical arguments for change and actively questioned them, opposed LSC plans and sought alternative routes to voice their views. Conclusion More research and consideration are needed regarding who should be involved, with what purpose and how. We argue that in practice two models of involvement, invited and uninvited participation, coexist and therefore interactions between the two should be given further consideration in LSC.

Doornbos, M. M., et al. (2013). "Using community-based participatory research to explore social determinants of women's mental health and barriers to help-seeking in three urban, ethnically diverse, impoverished, and underserved communities." Arch Psychiatr Nurs **27**(6): 278-284.

> Depression and anxiety are significant mental health issues that affect urban, ethnically diverse, impoverished women disproportionately. This study sought to identify social determinants of mental health and barriers to help-seeking for this population. Using community based participatory research and focus groups, sixty-one Black, Hispanic, and White women identified economic, family, cultural, and neighborhood issues as perceived determinants of their depression/anxiety. They identified practical, psychosocial, and cultural barriers to their help-seeking behavior. These results can promote women's health by fostering an understanding of social factors as perceived determinants of depression/anxiety and shaping practice and policy initiatives that foster positive aggregate outcomes.

Doroud, N., et al. (2015). "Recovery as an occupational journey: A scoping review exploring the links between occupational engagement and recovery for people with enduring mental health issues." Aust Occup Ther J **62**(6): 378-392.

> BACKGROUND/AIM: Mental health recovery can be defined in variety of different ways. First person accounts of people experiencing mental health issues and qualitative studies of recovery suggest engaging in personally meaningful and socially valued occupations is important during the process of recovering. This scoping review sought to explore how occupational engagement

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and recovery are interrelated. METHODS: Using Arksey and O'Malley's (2005) framework to guide the scoping review, searches of four electronic databases, manual citation tracking, and key authors' publications were conducted. Seventeen studies, published in the last 30 years, relevant to the topic were identified. Each was reviewed and data extracted to categorise the similarities and differences into themes. RESULTS: Most studies used qualitative, phenomenological and narrative research approaches. Findings across the studies indicate recovery is an ongoing occupational process that seems to involve experiences of gradual re-engagement, engaging within the stream of everyday occupational life, and full community participation. Engaging in meaningful and valued occupations appears to support recovering through fostering connectedness, hope, identity, meaning, and empowerment; establishing structured routines and assisting people in managing illness. CONCLUSION: This scoping review indicates occupational engagement is an important dimension of the recovery process: recovering is experienced through engaging in occupations, which, in turn, fosters personal recovery. Employment and volunteering have received most attention in studies of occupation and recovery. A broader view of the experiences and factors involved in the processes of 'occupational recovery' warrants further exploration to advance theory and inform recovery-oriented occupational therapy practice.

Dunn, L. B., et al. (2009). "Worth the risk? Relationship of incentives to risk and benefit perceptions and willingness to participate in schizophrenia research." Schizophr Bull **35**(4): 730-737.

OBJECTIVE: Providing incentives for research participation is widely practiced but minimally studied. In schizophrenia research, questions about capacity to consent and potential vulnerability may raise concerns when offering incentives for participation. Despite empirical attention focused on consent and decision-making capacity in schizophrenia, the issue of incentives has been essentially ignored. We examined willingness to participate in research, in relation to perceived risks and benefits, among people with schizophrenia and schizoaffective disorder. METHOD: Forty-six people with schizophrenia or schizoaffective disorder rated perceived risks and benefits of 5 hypothetical research vignettes. They also indicated whether they would be willing to participate at each of 5 incentive levels (including no compensation). Cognition was assessed with Mattis Dementia Rating Scale. RESULTS: Ratings of risk and potential personal benefit were inversely correlated. For all scenarios, significant correlations were found between perceived risk and willingness to participate for greater compensation. Conversely, lower perceived likelihood of benefit was associated with a higher compensation threshold for participation in each scenario. Even at the highest proffered payment level for each scenario, however, a substantial proportion of respondents were not willing to participate. Risk assessment and willingness to participate (at all levels of compensation) were not associated with demographic variables or cognitive status. CONCLUSIONS: Determining whether incentives impede voluntarism remains an important task for empirical ethics research. Assessing potential research participants' understanding and perceptions of risks, benefits, and alternatives to participation will help ensure that informed consent fulfills its mission--embodying the ethical principle of respect for persons.

Ellison, M. L., Belanger, L. K., Niles, B. L., et al. (2018). "Explication and Definition of Mental Health Recovery: A Systematic Review." Adm Policy Ment Health **45**(1): 91-102.

This review assessed the concordance of the literature on recovery with the definition and components of recovery developed by the Substance Abuse and Mental Health Services

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Administration (SAMHSA). Each SAMHSA identified recovery component was first explicated with synonyms and keywords and made mutually exclusive by authors. Inter-rater reliability was established on the coding of the presence of 17 recovery components and dimensions in 67 literature reviews on the recovery concept in mental health. The review indicated that concordance varied across SAMHSA components. The components of recovery with greatest concordance were: individualized/person centered, empowerment, purpose, and hope.

Elwood Martin, R., et al. (2009). "The development of participatory health research among incarcerated women in a Canadian prison." Int J Prison Health **5**(2): 95-107.

This paper describes the development of a unique prison participatory research project, in which incarcerated women formed a research team, the research activities and the lessons learned. The participatory action research project was conducted in the main short sentence minimum/medium security women's prison located in a Western Canadian province. An ethnographic multi-method approach was used for data collection and analysis. Quantitative data was collected by surveys and analysed using descriptive statistics. Qualitative data was collected from orientation package entries, audio recordings, and written archives of research team discussions, forums and debriefings, and presentations. These data and ethnographic observations were transcribed and analysed using iterative and interpretative qualitative methods and NVivo 7 software. Up to 15 women worked each day as prison research team members; a total of 190 women participated at some time in the project between November 2005 and August 2007. Incarcerated women peer researchers developed the research processes including opportunities for them to develop leadership and technical skills. Through these processes, including data collection and analysis, nine health goals emerged. Lessons learned from the research processes were confirmed by the common themes that emerged from thematic analysis of the research activity data. Incarceration provides a unique opportunity for engagement of women as expert partners alongside academic researchers and primary care workers in participatory research processes to improve their health.

Fanner, D. et Urquhart, C. (2008). "Bibliotherapy for mental health service users Part 1: a systematic review." Health Info Libr J **25**(4): 237-252.

AIMS AND OBJECTIVES: UK health policy advocates a patient-centred approach to patient care. Library services could serve the rehabilitation needs of mental health service users through bibliotherapy (the use of written, audio, or e-learning materials to provide therapeutic support). Part 1 of a two part article describes a systematic review of the evidence for the effectiveness of bibliotherapy in mental health services. METHODS: The systematic review of the literature used Cochrane guidelines, together with an overview of evaluations of bibliotherapy initiatives, and assessments of the needs of adult mental health service users for rehabilitation support. RESULTS: The evidence strongly suggests that library-based interventions and the provision of information could be beneficial for service users and economical for the health service in assisting treatment of a range of conditions. At present, public libraries in the UK are developing basic bibliotherapy services. CONCLUSIONS: Librarians, including librarians working for the health service, might provide more sophisticated bibliotherapy services, but the evidence to guide delivery is limited.

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Finke, E. H., et al. (2008). "A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication." J Clin Nurs **17**(16): 2102-2115.

> AIMS AND OBJECTIVES: To systematically review the research regarding communication between nurses and patients with complex communication needs (CCN). The research was reviewed with respect to the following themes: (a) the importance of communication; (b) the barriers to effective communication; (c) the supports needed for effective communication; and (d) recommendations for improving the effectiveness of communication between nurses and patients with CCN. Augmentative and alternative communication (AAC) strategies that can be used by nurses to facilitate more effective communication with patients with CCN are discussed. BACKGROUND: Effective nurse-patient communication is critical to efficient care provision. Difficulties in communication between nurses and patients arise when patients are unable to speak. This problem is further complicated because nurses typically receive little or no training in how to use AAC to communicate with patients with CCN. DESIGN: Systematic review. METHOD: This paper reviewed the published research focusing on the perspectives of nurses, patients with CCN and their caregivers regarding the challenges to effective communication between nurses and patients with CCN. Further, specific strategies (i.e., using AAC) that nurses can use to improve and facilitate communication with patients with CCN are provided. CONCLUSIONS: Communication between nurses and patients is critical to providing and receiving quality care. Nurses and patients have reported concern and frustration when communication is not adequate. Using AAC strategies will help nurses and patients better communicate with each other when speech is not an option. RELEVANCE TO CLINICAL PRACTICE: Communication with all patients is very important to the provision of quality nursing care. Communication cannot always be achieved using the speech modality. Nurses need to have tools and skills that will allow them to communicate with all of their patients whether or not they can speak.

Fisher, A., Manicavasagar, V., Sharpe, L., et al. (2018). "A qualitative exploration of patient and family views and experiences of treatment decision-making in bipolar II disorder." J Ment Health **27**(1): 66-79.

> BACKGROUND: Treatment decision-making in bipolar II disorder (BPII) is challenging, yet the decision support needs of patients and family remain unknown. AIM: To explore patient and family perspectives of treatment decision-making in BPII. METHOD: Semistructured, qualitative interviews were conducted with 28 patients with BPII-diagnosis and 13 family members with experience in treatment decision-making in the outpatient setting. Interviews were audiotaped, transcribed verbatim and analysed thematically using framework methods. Participant demographics, clinical characteristics and preferences for patient decision-making involvement were assessed. RESULTS: Four inter-related themes emerged: (1) Attitudes and response to diagnosis and treatment; (2) Influences on decision-making; (3) The nature and flow of decision-making; (4) Decision support and challenges. Views differed according to patient involvement preferences, time since diagnosis and patients' current mood symptoms. CONCLUSIONS: This is the first known study to provide in-depth patient and family insights into the key factors influencing BPII treatment decision-making, and potential improvements and challenges to this process. Findings will inform the development of BPII treatment decision-making resources that better meet the informational and decision-support priorities of end users. DECLARATION OF INTEREST: This research was partly funded by a Postgraduate Research Grant awarded to the first author by the University of Sydney. No conflicts of interest declared.

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Fortuna, K. L., Naslund, J. A., LaCroix, J. M., et al. (2020). "Digital Peer Support Mental Health Interventions for People With a Lived Experience of a Serious Mental Illness: Systematic Review." JMIR Ment Health **7**(4): e16460.

BACKGROUND: Peer support is recognized globally as an essential recovery service for people with mental health conditions. With the influx of digital mental health services changing the way mental health care is delivered, peer supporters are increasingly using technology to deliver peer support. In light of these technological advances, there is a need to review and synthesize the emergent evidence for peer-supported digital health interventions for adults with mental health conditions. OBJECTIVE: The aim of this study was to identify and review the evidence of digital peer support interventions for people with a lived experience of a serious mental illness. METHODS: This systematic review was conducted using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) procedures. The PubMed, Embase, Web of Science, Cochrane Central, CINAHL, and PsycINFO databases were searched for peer-reviewed articles published between 1946 and December 2018 that examined digital peer support interventions for people with a lived experience of a serious mental illness. Additional articles were found by searching the reference lists from the 27 articles that met the inclusion criteria and a Google Scholar search in June 2019. Participants, interventions, comparisons, outcomes, and study design (PICOS) criteria were used to assess study eligibility. Two authors independently screened titles and abstracts, and reviewed all full-text articles meeting the inclusion criteria. Discrepancies were discussed and resolved. All included studies were assessed for methodological quality using the Methodological Quality Rating Scale. RESULTS: A total of 30 studies (11 randomized controlled trials, 2 quasiexperimental, 15 pre-post designs, and 2 qualitative studies) were included that reported on 24 interventions. Most of the studies demonstrated feasibility, acceptability, and preliminary effectiveness of peer-to-peer networks, peer-delivered interventions supported with technology, and use of asynchronous and synchronous technologies. CONCLUSIONS: Digital peer support interventions appear to be feasible and acceptable, with strong potential for clinical effectiveness. However, the field is in the early stages of development and requires well-powered efficacy and clinical effectiveness trials. TRIAL REGISTRATION: PROSPERO CRD42020139037; https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID= 139037.

Franks, W. L. M., Crozier, K. E. et Penhale, B. L. M. (2017). "Women's mental health during pregnancy: A participatory qualitative study." Women Birth **30**(4): e179-e187.

BACKGROUND/OBJECTIVES: British public health and academic policy and guidance promotes service user involvement in health care and research, however collaborative research remains underrepresented in literature relating to pregnant women's mental health. The aim of this participatory research was to explore mothers' and professionals' perspectives on the factors that influence pregnant women's mental health. METHOD: This qualitative research was undertaken in England with the involvement of three community members who had firsthand experience of mental health problems during pregnancy. All members of the team were involved in study design, recruitment, data generation and different stages of thematic analysis. Data were transcribed for individual and group discussions with 17 women who self-identified as experiencing mental health problems during pregnancy and 15 professionals who work with this group. Means of establishing trustworthiness included triangulation, researcher reflexivity, peer debriefing and comprehensive data analysis. FINDINGS: Significant areas of commonality

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were identified between mothers' and professionals' perspectives on factors that undermine women's mental health during pregnancy and what is needed to support women's mental health. Analysis of data is provided with particular reference to contexts of relational, systemic and ecological conditions in women's lives. CONCLUSIONS: Women's mental health is predominantly undermined or supported by relational, experiential and material factors. The local context of socio-economic deprivation is a significant influence on women's mental health and service requirements.

Fukui, S., et al. (2011). "Effect of Wellness Recovery Action Plan (WRAP) participation on psychiatric symptoms, sense of hope, and recovery." Psychiatr Rehabil J **34**(3): 214-222.

OBJECTIVE: Self-management of psychiatric illness is a central tenet of consumer-directed mental health treatment. While several manualized self-management programs have been developed in recent years, the most widely disseminated is the Wellness Recovery Action Plan (WRAP). This study examined the effects of WRAP participation on psychiatric symptoms, hope, and recovery outcomes for people with severe and persistent mental illness. METHODS: A quasi-experimental study, with an experimental (n=58) and a comparison (n=56) group was conducted. WRAP sessions (8-12 week) were facilitated by one staff person and one peer worker at five community mental health centers in a Midwestern state. The Modified Colorado Symptom Index, the State Hope Scale, and the Recovery Markers Questionnaire (RMQ) were employed at the first and last WRAP sessions, as well as six months following the intervention. Repeated measures analysis of covariance and planned comparisons before and after the intervention were conducted. RESULTS: Findings revealed statistically significant group intervention effects for symptoms and hope, but not for RMQ. Planned comparisons showed statistically significant improvements for the experimental group in psychiatric symptoms and hope after the intervention, while non-significant changes occurred in the comparison group. CONCLUSIONS AND IMPLICATIONS FOR PRACTICE: The study results offer promising evidence that WRAP participation has a positive effect on psychiatric symptoms and feelings of hopefulness. If recovery is the guiding vision for mental health system reform, the study results provide evidence that WRAP programming may warrant a place in the current array of services offered through the publicly funded mental health system.

Furimsky, I., et al. (2008). "Strategies to enhance patient recruitment and retention in research involving patients with a first episode of mental illness." Contemp Clin Trials **29**(6): 862-866.

Recruitment and retention of research participants is often the most labor-intensive and difficult component of clinical trials. Poor recruitment and retention frequently pose as a major barrier in the successful completion of clinical trials. In fact, many studies are prematurely terminated, or their findings questioned due to low recruitment and retention rates. The conduct of clinical trials involving youth with a first episode of mental illness comes with additional challenges in recruitment and retention including barriers associated with engagement and family involvement. To develop effective early interventions for first episode mental illness, it is necessary to develop strategies to enhance recruitment and retention in this patient population. This article presents the recruitment and retention challenges experienced in two clinical trials: one involving participants experiencing a first episode of depression and one involving participants experiencing a first episode psychosis. Challenges with recruitment and retention are identified and reviewed at both the patient level and clinician level. Strategies that were

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implemented to enhance recruitment and retention in these two studies are also discussed.
Finally, ethical issues to consider when implementing these strategies are also highlighted.

Gammon, D., Strand, M., Eng, L. S., et al. (2017). "Shifting Practices Toward Recovery-Oriented Care
Through an E-Recovery Portal in Community Mental Health Care: A Mixed-Methods Exploratory Study."
J Med Internet Res **19**(5): e145.

> BACKGROUND: Mental health care is shifting from a primary focus on symptom reduction
> toward personal recovery-oriented care, especially for persons with long-term mental health
> care needs. Web-based portals may facilitate this shift, but little is known about how such tools
> are used or the role they may play in personal recovery. OBJECTIVE: The aim was to illustrate
> uses and experiences with the secure e-recovery portal "ReConnect" as an adjunct to ongoing
> community mental health care and explore its potential role in shifting practices toward
> recovery. METHODS: ReConnect was introduced into two Norwegian mental health care
> communities and used for 6 months. The aim was to support personal recovery and
> collaboration between service users and health care providers. Among inclusion criteria for
> participation were long-term care needs and at least one provider willing to interact with service
> users through ReConnect. The portal was designed to support ongoing collaboration as each
> service user-provider dyad/team found appropriate and consisted of (1) a toolbox of resources
> for articulating and working with recovery processes, such as status/goals/activities relative to
> life domains (eg, employment, social network, health), medications, network map, and exercises
> (eg, sleep hygiene, mindfulness); (2) messaging with providers who had partial access to toolbox
> content; and (3) a peer support forum. Quantitative data (ie, system log, questionnaires) were
> analyzed using descriptive statistics. Qualitative data (eg, focus groups, forum postings) are
> presented relative to four recovery-oriented practice domains: personally defined recovery,
> promoting citizenship, working relationships, and organizational commitment. RESULTS: Fifty-six
> participants (29 service users and 27 providers) made up 29 service user-provider dyads. Service
> users reported having 11 different mental health diagnoses, with a median 2 (range 1-7)
> diagnoses each. The 27 providers represented nine different professional backgrounds. The
> forum was the most frequently used module with 1870 visits and 542 postings. Service users'
> control over toolbox resources (eg, defining and working toward personal goals), coupled with

Garcia, C., et al. (2012). "Development of project wings home visits, a mental health intervention for
Latino families using community-based participatory research." Health Promot Pract **13**(6): 755-762.

> As the Latino population in the United States experiences rapid growth, the well-being of Latino
> adolescents is a growing concern because of their high rates of mental health problems. Latino
> adolescents have higher rates of mental health problems than their peers, including depressive
> symptoms, suicide attempts, and violence. Sophisticated, realistic health promotion efforts are
> needed to reduce these risk behaviors and enhance protective factors. Parents and schools can
> be key protective factors, or assets, in adolescents' lives. This article details the steps
> undertaken to develop Project Wings Home Visits, a collaborative school-based, community-
> linked mental health promotion intervention for Latino adolescents and their families. Core to
> the intervention is the use of a community health worker model to provide home-based
> outreach and education to parents of Latino adolescents. The intervention was developed using
> a community-based participatory research approach that involved the cooperation of a
> community health care system, a public high school, and a university. Our process demonstrates

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the benefits, strengths, and challenges of using community-based participatory research in creating and implementing health promotion interventions.

Garland, A. F., et al. (2006). "Research–practice partnership in mental health: Lessons from participants." Administration and Policy in Mental Health and Mental Health Services Research **33**(5): 517-528.

Gibson, A., Welsman, J. et Britten, N. (2017). "Evaluating patient and public involvement in health research: from theoretical model to practical workshop." Health Expect **20**(5): 826-835.

BACKGROUND: There is a growing literature on evaluating aspects of patient and public involvement (PPI). We have suggested that at the core of successful PPI is the dynamic interaction of different forms of knowledge, notably lay and professional. We have developed a four-dimensional theoretical framework for understanding these interactions. AIM: We explore the practical utility of the theoretical framework as a tool for mapping and evaluating the experience of PPI in health services research. METHODS: We conducted three workshops with different PPI groups in which participants were invited to map their PPI experiences on wall charts representing the four dimensions of our framework. The language used to describe the four dimensions was modified to make it more accessible to lay audiences. Participants were given sticky notes to indicate their own positions on the different dimensions and to write explanatory comments if they wished. Participants' responses were then discussed and analysed as a group. RESULTS: The three groups were distinctive in their mapped responses suggesting different experiences in relation to having a strong or weak voice in their organization, having few or many ways of getting involved, addressing organizational or public concerns and believing that the organization was willing to change or not. DISCUSSION: The framework has practical utility for mapping and evaluating PPI interactions and is sensitive to differences in PPI experiences within and between different organizations. The workshops enabled participants to reflect collaboratively on their experiences with a view to improving PPI experiences and planning for the future.

Gilburt, H., et al. (2008). "The importance of relationships in mental health care: A qualitative study of service users' experiences of psychiatric hospital admission in the UK." BMC Health Serv Res **8**(1): 92.

Gillard, S., Bremner, S., Foster, R., et al. (2020). "Peer support for discharge from inpatient to community mental health services: Study protocol clinical trial (SPIRIT Compliant)." Medicine (Baltimore) **99**(10): e19192.

INTRODUCTION: In the period shortly after discharge from inpatient to community mental health care, people are at increased risk of self-harm, suicide, and readmission to hospital. Discharge interventions including peer support have shown potential, and there is some evidence that community-based peer support reduces readmissions. However, systematic reviews of peer support in mental health services indicate poor trial quality and a lack of reporting of how peer support is distinctive from other mental health support. This study is designed to establish the clinical and cost effectiveness of a peer worker intervention to support discharge from inpatient to community mental health care, and to address issues of trial quality and clarity of reporting of peer support interventions. METHODS: This protocol describes an individually randomized controlled superiority trial, hypothesizing that people offered a peer worker discharge intervention in addition to usual follow-up care in the community are less

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likely to be readmitted in the 12 months post discharge than people receiving usual care alone. A total of 590 people will be recruited shortly before discharge from hospital and randomly allocated to care as usual plus the peer worker intervention or care as usual alone. Manualized peer support provided by trained peer workers begins in hospital and continues for 4 months in the community post discharge. Secondary psychosocial outcomes are assessed at 4 months post discharge, and service use and cost outcomes at 12 months post discharge, alongside a mixed methods process evaluation. DISCUSSION: Clearly specified procedures for sequencing participant allocation and for blinding assessors to allocation, plus full reporting of outcomes, should reduce risk of bias in trial findings and contribute to improved quality in the peer support evidence base. The involvement of members of the study team with direct experience of peer support, mental distress, and using mental health services, in coproducing the intervention and designing the trial, ensures that we theorize and clearly describe the peer worker intervention, and evaluate how peer support is related to any change in outcome. This is an important methodological contribution to the evidence base. TRIAL REGISTRATION: This study was prospectively registered as ISRCTN 10043328 on November 28, 2016.

Godfrey, M., et al. (2013). "Developing and implementing an integrated delirium prevention system of care: a theory driven, participatory research study." BMC Health Serv Res **13**: 341.

BACKGROUND: Delirium is a common complication for older people in hospital. Evidence suggests that delirium incidence in hospital may be reduced by about a third through a multi-component intervention targeted at known modifiable risk factors. We describe the research design and conceptual framework underpinning it that informed the development of a novel delirium prevention system of care for acute hospital wards. Particular focus of the study was on developing an implementation process aimed at embedding practice change within routine care delivery. METHODS: We adopted a participatory action research approach involving staff, volunteers, and patient and carer representatives in three northern NHS Trusts in England. We employed Normalization Process Theory to explore knowledge and ward practices on delirium and delirium prevention. We established a Development Team in each Trust comprising senior and frontline staff from selected wards, and others with a potential role or interest in delirium prevention. Data collection included facilitated workshops, relevant documents/records, qualitative one-to-one interviews and focus groups with multiple stakeholders and observation of ward practices. We used grounded theory strategies in analysing and synthesising data. RESULTS: Awareness of delirium was variable among staff with no attention on delirium prevention at any level; delirium prevention was typically neither understood nor perceived as meaningful. The busy, chaotic and challenging ward life rhythm focused primarily on diagnostics, clinical observations and treatment. Ward practices pertinent to delirium prevention were undertaken inconsistently. Staff welcomed the possibility of volunteers being engaged in delirium prevention work, but existing systems for volunteer support were viewed as a barrier. Our evolving conception of an integrated model of delirium prevention presented major implementation challenges flowing from minimal understanding of delirium prevention and securing engagement of volunteers alongside practice change. The resulting Prevention of Delirium (POD) Programme combines a multi-component delirium prevention and implementation process, incorporating systems and mechanisms to introduce and embed delirium prevention into routine ward practices. CONCLUSIONS: Although our substantive interest was in delirium prevention, the conceptual and methodological strategies pursued have implications for implementing and sustaining practice and service improvements more broadly. STUDY REGISTRATION: ISRCTN65924234.

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Godrie, B. (2015). "L'autre côté de la clôture. Quand le monde de la santé mentale et de la rue rencontre celui de la recherche." <u>Santé mentale au Québec</u> **40**(1): 67-80.
http://id.erudit.org/iderudit/1032383ar

> Si les thèmes du patient partenaire et du patient collaborateur sont de plus en plus en vogue dans le domaine de la recherche en santé mentale, les dynamiques relationnelles entre patients et chercheurs et les enjeux qu'elles soulèvent sont relativement peu documentés au Québec. Cet article vise à alimenter le débat sur ces dynamiques à partir d'un cas d'étude : la participation d'un pair à deux équipes de recherche d'un projet de recherche et de démonstration dans le champ de la santé mentale et de l'itinérance. Le récit de son expérience dans le projet explore notamment la manière dont les réalités qu'il vit - au croisement des problèmes de santé mentale, de son expérience de la rue et de la consommation - ont un impact sur les relations qu'il entretient avec ses collègues. Réciproquement, ses conditions de travail semblent l'affecter de manière négative et produire une perte d'identité conduisant, entre autres, à son départ du projet. L'analyse tend à montrer que les conflits vécus entre le pair et ses collègues sont le reflet de hiérarchies qui existent entre les statuts et les savoirs reconnus ou à reconnaître dans le champ de la recherche.

Gondek, D., Edbrooke-Childs, J., Velikonja, T., et al. (2017). "Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review." <u>Clin Psychol Psychother</u> **24**(4): 870-886.

> Implementation of person-centred care has been widely advocated across various health settings and patient populations, including recent policy for child and family services. Nonetheless, evidence suggests that service users are rarely involved in decision-making, whilst their preferences and goals may be often unheard. The aim of the present research was to systematically review factors influencing person-centred care in mental health services for children, young people and families examining perspectives from professionals, service users and carers. This was conducted according to best practice guidelines, and seven academic databases were searched. Overall, 23 qualitative studies were included. Findings from the narrative synthesis of the facilitators and barriers are discussed in light of a recently published systematic review examining person-centred care in mental health services for adults. Facilitators and barriers were broadly similar across both settings. Training professionals in person-centred care, supporting them to use it flexibly to meet the unique needs of service users whilst also being responsive to times when it may be less appropriate and improving both the quantity and quality of information for service users and carers are key recommendations to facilitate person-centred care in mental health services with children, young people and families. Copyright (c) 2016 John Wiley & Sons, Ltd. KEY PRACTITIONERS MESSAGES: As research shows, children and young people are rarely actively involved in their treatment within mental health services. This is despite a strong recent emphasis on providing care within child and young people mental health services according to person-centred principles. Still, there is little known about factors affecting provision of person-centred care with this population. As found by the current study, the most commonly reported factors affecting provision of person-centred care were information sharing (in an appropriate amount and at a right time), listening, respecting and validating, quality of relationship and support, capacity of children and young people to be involved in their care, parental involvement and shortage of resources. These factors were cited as both facilitators and barriers and were found to be universally important

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by service users, their carers and professional working at the services. The key factors were broadly similar to those reported among adults, particularly regarding information sharing/communication, capacity of service users to be involved and available resources. The main difference was related to a more complex role of a carer in children/young people services. The key recommendations of the review to improve provision of person-centred care are providing professionals with more training in using the approach, supporting them to use it flexibly to meet the unique needs of service users whilst also being responsive to times when it may be less appropriate and improving both the quantity and quality of information for service users.

Granosik, M. et Foucart, J. (2011). "The third party and the (professional) stranger: personal and interactional approach to participative research
http://www.cairn.info/revue-pensee-plurielle-2011-3-page-41.htm

Grealish, A., Tai, S., Hunter, A., et al. (2017). "Does empowerment mediate the effects of psychological factors on mental health, well-being, and recovery in young people?" Psychol Psychother **90**(3): 314-335.

OBJECTIVES: There is consensus that empowerment is key to recovery from mental health problems, enabling a person to take charge of their life and make informed choices and decisions about their life. However, little is known about the mechanisms through which empowerment affects mental health in young people. The current study involved young people aged 16-29 years and examined empowerment as a potential mediator of the relationship between psychological factors (psychosocial, cognition, coping, and control) and mental health, well-being, and recovery from personal problems. METHODS: A cross-sectional, Internet-based questionnaire study recruited 423 young people aged between 16 and 29 attending universities in England (n = 336) and Ireland (n = 87). Psychological factors, mental well-being, empowerment, and recovery from personal problems were measured using self-report measures. RESULTS: Mediation analysis in both the single and one over-arching mediator models revealed that empowerment mediates the relationship between psychological factors (psychosocial, self-efficacy, thinking style, coping, and control) and mental health, well-being, and recovery from general life problems. CONCLUSIONS: This study demonstrates the importance of empowerment, showing that it mediates the relationship between psychological processes and mental health, well-being, and recovery in young people. Clinical implications for working with young people within mental health services, and facilitating their empowerment are discussed. PRACTITIONER POINTS: Empowerment is currently a poorly defined concept. This study demonstrates how empowerment mediates the relationship between psychological processes and mental health, well-being, and recovery in young people. Clinicians working with young people might benefit from a structured means of understanding and assessing the different ways in which individuals manage their thinking styles. Empowerment in young people is influenced by the manner in which clinicians facilitate them in establishing social networks in support of employment, education, family/social relations and to encourage young people to take an assertive role in their own care.

Groß, S. E., Zielasek, J., Kitzig, F., et al. (2021). "[Self-Perception and External Perception of Peer Support Workers in Clinical Psychiatric Practice]." Psychiatr Prax **48**(1): 44-48.

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OBJECTIVE: Since 2016, peer support workers (PSW) have been working in a clinical group with nine psychiatric clinics. The aim of this study was to collect expectations and experiences with peer support work. METHOD: Twelve PSW and 32 clinicians (key informants, KI) from all clinics participated in an anonymous, written survey. RESULTS: Both PSW and KI evaluated the overall importance of peer support, the cooperation between PSW and the clinical staff and the support from supervisors positively. KI rated the importance of peer support higher than the PSW themselves. PSW expressed the wish to act more independently. Compared to the self-perception of PSW, KI experienced them more insecure and burdened. CONCLUSION: Our findings speak in favor of a high level of satisfaction with peer support work, but they also point to critical differences between external and self-perceptions of PSW. Qualitative and more extensive quantitative surveys are required.

Grundy, A. C., Walker, L., Meade, O., et al. (2017). "Evaluation of a co-delivered training package for community mental health professionals on service user- and carer-involved care planning." J Psychiatr Ment Health Nurs **24**(6): 358-366.

WHAT IS KNOWN ON THE SUBJECT?: There is consistent evidence that service users and carers feel marginalized in the process of mental health care planning. Mental health professionals have identified ongoing training needs in relation to involving service users and carers in care planning. There is limited research on the acceptability of training packages for mental health professionals which involve service users and carers as co-facilitators. WHAT DOES THIS PAPER ADD TO EXISTING KNOWLEDGE?: A co-produced and co-delivered training package on service user- and carer-involved care planning was acceptable to mental health professionals. Aspects of the training that were particularly valued were the co-production model, small group discussion and the opportunity for reflective practice. The organizational context of care planning may need more consideration in future training models. WHAT ARE THE IMPLICATIONS FOR PRACTICE?: Mental health nurses using co-production models of delivering training to other mental health professionals can be confident that such initiatives will be warmly welcomed, acceptable and engaging. On the basis of the results reported here, we encourage mental health nurses to use co-production approaches more often. Further research will show how clinically effective this training is in improving outcomes for service users and carers. ABSTRACT: Background There is limited evidence for the acceptability of training for mental health professionals on service user- and carer-involved care planning. Aim To investigate the acceptability of a co-delivered, two-day training intervention on service user- and carer-involved care planning. Methods Community mental health professionals were invited to complete the Training Acceptability Rating Scale post-training. Responses to the quantitative items were summarized using descriptive statistics (Miles,), and qualitative responses were coded using content analysis (Weber,). Results Of 350 trainees, 310 completed the questionnaire. The trainees rated the training favourably (median overall TARS scores = 56/63; median 'acceptability' score = 34/36; median 'perceived impact' score = 22/27). There were six qualitative themes: the value of the co-production model; time to reflect on practice; delivery preferences; comprehensiveness of content; need to consider organizational context; and emotional response. Discussion The training was found to be acceptable and comprehensive with participants valuing the co-production model. Individual differences were apparent in terms of delivery preferences and emotional reactions. There may be a need to further address the organizational context of care planning in future training. Implications for practice Mental health nurses should use co-production models of continuing professional development training that involve service users and carers as co-facilitators.

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Gunasekara, I., Patterson, S. et Scott, J. G. (2017). "'What makes an excellent mental health doctor?' A response integrating the experiences and views of service users with critical reflections of psychiatrists." Health Soc Care Community **25**(6): 1752-1762.

> While therapeutic relationships are appropriately recognised as the foundation of mental health service, service users commonly report suboptimal experiences. With shared understanding critical to improvement in practice, we explored service users' experiences and expectations of psychiatrists and consultations, engaging psychiatrists throughout the process. Using an iterative qualitative approach we co-produced a response to the question 'what makes an excellent mental health doctor?' Experiences and expectations of psychiatrists were explored in interviews with 22 service users. Data collection, analysis and interpretation were informed by consultation with peer workers. Findings were contextualised in formal consultations with psychiatrists. As 'masters of their craft', excellent mental health doctors engage authentically with service users as people (not diagnoses). They listen, validate experiences and empathise affectively and cognitively. They demonstrate phronesis, applying clinical knowledge compassionately. Psychiatrists share service users' aspiration of equitable partnership but competing demands and 'professional boundaries' constrain engagement. Consistent delivery of the person-centred, recovery-oriented care promoted by policy and sought by service users will require substantial revision of the structure and priorities of mental health services. The insights and experiences of service users must be integral to medical education, and systems must provide robust support to psychiatrists.

Hacking, S., et al. (2008). "Evaluating the impact of participatory art projects for people with mental health needs." Health Soc Care Community **16**(6): 638-648.

> Participatory art projects for people with mental health needs typically claim outcomes such as improvements in confidence, self-esteem, social participation and mental health. However, such claims have rarely been subjected to robust outcome research. This paper reports outcomes from a survey of 44 female and 18 male new art project participants attending 22 art projects in England, carried out as part of a national evaluation. Outcomes were quantified through self-completed questionnaires on first entry to the project, during January to March of 2006, and 6 months later. The questionnaires included three measures: empowerment, mental health [Clinical Outcomes in Routine Evaluation (CORE)] and social inclusion. Paired t-tests were used to compare overall change, and mixed model repeated measures analysis of variance to compare subgroups, including age, gender, educational level, mental health and level of participation. Results showed significant improvements in empowerment (P = 0.01), mental health (P = 0.03) and social inclusion (P = 0.01). Participants with higher CORE scores, no new stress in their lives and positive impressions of the impact of arts on their life benefited most over all three measures. Positive impressions of the impact of arts were significantly associated with improvement on all three measures, but the largest effect was for empowerment (P = 0.002) rather than mental health or social inclusion. This study suggests that arts participation positively benefits people with mental health difficulties. Arts participation increased levels of empowerment and had potential to impact on mental health and social inclusion.

Happell, B., Gordon, S., Bocking, J., et al. (2018). "Mental Health Researchers' Views About Service User Research: A Literature Review." Issues Ment Health Nurs **39**(12): 1010-1016.

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Services users are becoming actively involved in mental health research. How this is perceived by other researchers is not well known. The aim of this article is to review the international literature exploring other mental health researchers' views of service users conducting research, between 1996 and 2016. Searches of multiple databases (PubMed, PsycINFO, CINAHL, and Google Scholar) were undertaken. Combinations of terms related to service user research and mental health researcher perspectives, views, and attitudes were used. Manual inquiry of reference lists was also undertaken. Relevant papers were coded by topic, location, study design, and other dimensions. Five articles met inclusion criteria. Most referred to perceived benefits, such as greater validity of research findings, challenges of collaborating with service users, and the validity of research findings. There was some evidence of more openness to mental health service users providing suggestions, preferably in early stages of the research process. Reluctance to co-research with service users was reported. There is limited research directly addressing other mental health researchers' views about service user research; barriers to inclusion (whether involvement, co-production or user-controlled) and creating incongruence with health policy statements. Further research to more fully understand these attitudes and how they might be influenced is warranted.

Hasan, A. et Musleh, M. (2017). "The impact of an empowerment intervention on people with schizophrenia: Results of a randomized controlled trial." Int J Soc Psychiatry **63**(3): 212-223.

AIMS: The aim of the study was to assess what empowerment intervention has on people with schizophrenia. METHODS: A randomized controlled trial was carried out between November 2015 and May 2016 involving 112 participants who had been diagnosed with schizophrenia. Patients, who were 18 years and above diagnosed with Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-V) schizophrenia or schizoaffective disorder from the outpatient mental health clinics in Jordan, were randomly assigned to take part in an intervention that consisted of receiving 6 weeks' worth of information booklets, with face to face discussions, while receiving their usual medication or allocated treatment as usual. The participants were assessed at baseline, immediately after the intervention and at 3-month follow-up. The primary outcome was a change in the helplessness score. Secondary outcomes were psychiatric symptoms, recovery rate, empowerment and quality of life. RESULTS: This study showed that people with schizophrenia in the intervention group showed more improvement in the helplessness score immediately post-intervention (F = 74.53, p < .001) and at 3-month follow-up (F = 75.56, p < .001), they reported significant improvements in all secondary outcomes. CONCLUSION: This study indicated that the empowering intervention was an effective intervention when integrated with treatment as usual.

Hawke, L. D., Relihan, J., Miller, J., et al. (2018). "Engaging youth in research planning, design and execution: Practical recommendations for researchers." Health Expect **21**(6): 944-949.

CONTEXT: Engaging youth as partners in academic research projects offers many benefits for the youth and the research team. However, it is not always clear to researchers how to engage youth effectively to optimize the experience and maximize the impact. OBJECTIVE: This article provides practical recommendations to help researchers engage youth in meaningful ways in academic research, from initial planning to project completion. These general recommendations can be applied to all types of research methodologies, from community action-based research to highly technical designs. RESULTS: Youth can and do provide valuable input into academic research projects when their contributions are authentically valued, their roles are clearly

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defined, communication is clear, and their needs are taken into account. Researchers should be aware of the risk of tokenizing the youth they engage and work proactively to take their feedback into account in a genuine way. Some adaptations to regular research procedures are recommended to improve the success of the youth engagement initiative. CONCLUSIONS: By following these guidelines, academic researchers can make youth engagement a key tenet of their youth-oriented research initiatives, increasing the feasibility, youth-friendliness and ecological validity of their work and ultimately improve the value and impact of the results their research produces.

Heslop, L., et al. (2000). "Improving continuity of care across psychiatric and emergency services: combining patient data within a participatory action research framework." J Adv Nurs **31**(1): 135-143.

Hofmann, W., et al. (2012). "[Reformed German psychiatry for empowerment of the patient]." Soins Psychiatr(283): 20-22.

The reform of psychiatry in Germany has seen the conversion of numerous psychiatric hospitals into general hospitals with a psychiatric department. With regard to nursing care, a two-year additional training is offered to professionals wishing to work in psychiatry. Finally, there exists within the population a marginalisation of psychotic patients or of those suffering from an addiction.

Huang, C., Plummer, V., Lam, L., et al. (2020). "Shared decision-making in serious mental illness: A comparative study." Patient Educ Couns **103**(8): 1637-1644.

OBJECTIVE: To compare consumer and mental health professionals' (MHPs) preferences for decision-making in China and Europe. METHODS: This study used cross-sectional design; Chinese data were collected by questionnaires and European data were obtained from the literature. Data were analysed using t-test, One-way ANOVA and Pearson correlation coefficient as appropriate. RESULTS: This study involved 800 people diagnosed with severe mental illness and 506 MHPs. Chinese participants rated lower scores on preference for participation in decision-making (PD = 1.88) and information (IN = 2.70) than European participants (PD = 2.05, IN = 2.83). Chinese consumers rated a higher score on IN (2.78) but lower on for PD (1.75) than MHPs (IN = 2.64, PD = 1.97). Chinese consumers' education level is positively associated with preference for PD and IN. The gender, occupation and age of Chinese MHPs are associated with preference for PD. CONCLUSION: Both Chinese and Europeans had preference for shared involvement in mental health, while the preference in China is less. Opinions of consumers and MHPs might be different, regarding the level of patient involvement in specific decisions. PRACTICE IMPLICATION: It is essential that consumers' preferences are understood for provision of optimal support for a shared decision-making approach.

Hultqvist, J., et al. (2015). "Empowerment and occupational engagement among people with psychiatric disabilities." Scand J Occup Ther **22**(1): 54-61.

BACKGROUND: Empowerment is essential in the rehabilitation process for people with psychiatric disabilities and knowledge about factors that may play a key role within this process would be valuable for further development of the day centre services. OBJECTIVE: The present study investigates day centre attendees' perceptions of empowerment. The aim was to investigate which factors show the strongest relationships to empowerment when considering

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occupational engagement, client satisfaction with day centres, and health-related and socio-demographic factors as correlates. METHODS: 123 Swedish day centre attendees participated in a cross-sectional study by completing questionnaires regarding empowerment and the targeted correlates. Data were analysed with non-parametric statistics. RESULTS: Empowerment was shown to be significantly correlated with occupational engagement and client satisfaction and also with self-rated health and symptoms rated by a research assistant. The strongest indicator for belonging to the group with the highest ratings on empowerment was self-rated health, followed by occupational engagement and symptom severity. IMPLICATIONS: Occupational engagement added to the beneficial influence of self-rated health on empowerment. Enabling occupational engagement in meaningful activities and providing occupations that can generate client satisfaction is an important focus for day centres in order to assist the attendees' rehabilitation process so that it promotes empowerment.

Hutchinson, A. et Lovell, A. (2013). "Participatory action research: Moving beyond the mental health 'service user'identity." J Psychiatr Ment Health Nurs **20**(7): 641-649.

Ibrahim, N., Thompson, D., Nixdorf, R., et al. (2020). "A systematic review of influences on implementation of peer support work for adults with mental health problems." Soc Psychiatry Psychiatr Epidemiol **55**(3): 285-293.

PURPOSE: The evidence base for peer support work in mental health is established, yet implementation remains a challenge. The aim of this systematic review was to identify influences which facilitate or are barriers to implementation of mental health peer support work. METHODS: Data sources comprised online databases (n = 11), journal table of contents (n = 2), conference proceedings (n = 18), peer support websites (n = 2), expert consultation (n = 38) and forward and backward citation tracking. Publications were included if they reported on implementation facilitators or barriers for formal face-to-face peer support work with adults with a mental health problem, and were available in English, French, German, Hebrew, Luganda, Spanish or Swahili. Data were analysed using narrative synthesis. A six-site international survey [Germany (2 sites), India, Israel, Tanzania, Uganda] using a measure based on the strongest influences was conducted. The review protocol was pre-registered (Prospero: CRD42018094838). RESULTS: The search strategy identified 5813 publications, of which 53 were included. Fourteen implementation influences were identified, notably organisational culture (reported by 53% of papers), training (42%) and role definition (40%). Ratings on a measure using these influences demonstrated preliminary evidence for the convergent and discriminant validity of the identified influences. CONCLUSION: The identified influences provide a guide to implementation of peer support. For services developing a peer support service, organisational culture including role support (training, role clarity, resourcing and access to a peer network) and staff attitudes need to be considered. The identified influences provide a theory base to prepare research sites for implementing peer support worker interventions.

Iliffe, S., et al. (2013). "The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies." Health Expect **16**(4): 351-361.

AIMS: (i) To describe patient and public involvement (PPI) in a network promoting research in dementia and neurodegenerative diseases, in terms of activity at the different stages of the research cycle and within the different levels of the research network. (ii) To use case studies to

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try and answer the question: what benefits (if any) does PPI in research bring to the research process? BACKGROUND: PPI in health research is a central part of government policy, but the evidence base underpinning it needs strengthening. PPI allows exploration of feasibility, acceptability and relevance of hypotheses, assists in the precise definition of research questions and increases accrual to studies. However, the measurement of outcomes is methodologically difficult, because the impact of lay researchers may occur through team interactions and be difficult to untangle from the efforts of professional researchers. Opportunities for PPI in rapidly progressive diseases may be limited, and involvement of people with marked cognitive impairment is particularly challenging. DESIGN: (i) Description of PPI within the DeNDRoN network. (ii) Case studies of three research projects which asked for extra help from centrally organized PPI. RESULTS: PPI in research projects on the DeNDRoN portfolio may function at different levels, occurring at project, local research network and national level. Case studies of three research projects show different roles for PPI in research and different functions for centrally organized PPI, including contribution to remedial action in studies that are not recruiting to target, solving problems because of the complexity and sensitivity of the research topic, and linking researchers to PPI resources. DISCUSSION: The case studies suggest that centrally organized PPI can have 'diagnostic' and remedial functions in studies that are struggling to recruit and serve as reinforcement for study-level PPI in the complex and sensitive research topics that are typical in neurodegenerative diseases research. PPI may be actively sought by researchers, but the infrastructure of PPI is not yet so widespread in the research community that lay researchers are easy to find; a centrally organized PPI resource can assist in this situation.

Israel, B. A., et al. (2001). "Community-based participatory research: policy recommendations for promoting a partnership approach in health research." Education for health **14**(2): 182-197.

Iyer, S. P., et al. (2015). "Consumer-Involved Participatory Research to Address General Medical Health and Wellness in a Community Mental Health Setting." Psychiatr Serv **66**(12): 1268-1270.

Barriers to sustainably implementing general medical interventions in community mental health (CMH) settings include role uncertainty, consumer engagement, workforce limitations, and sustainable reimbursement. To address these barriers, this project used a community-partnered participatory research framework to create a stakeholder-based general medical and wellness intervention in a large CMH organization, with consumers involved in all decision-making processes. Consumers faced practical barriers to participating in organizational decision making, but their narratives were critical in establishing priorities and ensuring sustainability. Addressing baseline knowledge and readiness of stakeholders and functional challenges to consumer involvement can aid stakeholder-based approaches to implementing general medical interventions in CMH settings.

Jana, A. K., et al. (2014). "Empowerment and its associations in schizophrenia: a cross-sectional study." Community Ment Health J **50**(6): 697-701.

Empowerment denotes a sense of personal competence which is considered an essential requisite of fair outcome in schizophrenia. The current study assessed empowerment along with other relevant variables in patients with schizophrenia and a comparison group. Hierarchical multiple linear regression analysis identified independent living skills survey score and perceived social support as predicting empowerment in patients with schizophrenia, suggesting a

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correlational relationship. Empowerment could be a treatment goal in schizophrenia and independent living skills as well as perceived social support could be the mediating factors.

Jennings, H., Slade, M., Bates, P., et al. (2018). "Best practice framework for Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement." BMC Psychiatry **18**(1): 213.

> BACKGROUND: Patient and Public Involvement (PPI) in mental health research is increasing, especially in early (pre-funding) stages. PPI is less consistent in later stages, including in analysing qualitative data. The aims of this study were to develop a methodology for involving PPI co-researchers in collaboratively analysing qualitative mental health research data with academic researchers, to pilot and refine this methodology, and to create a best practice framework for collaborative data analysis (CDA) of qualitative mental health research. METHODS: In the context of the RECOLLECT Study of Recovery Colleges, a critical literature review of collaborative data analysis studies was conducted, to identify approaches and recommendations for successful CDA. A CDA methodology was developed and then piloted in RECOLLECT, followed by refinement and development of a best practice framework. RESULTS: From 10 included publications, four CDA approaches were identified: (1) consultation, (2) development, (3) application and (4) development and application of coding framework. Four characteristics of successful CDA were found: CDA process is co-produced; CDA process is realistic regarding time and resources; demands of the CDA process are manageable for PPI co-researchers; and group expectations and dynamics are effectively managed. A four-meeting CDA process was piloted to co-produce a coding framework based on qualitative data collected in RECOLLECT and to create a mental health service user-defined change model relevant to Recovery Colleges. Formal and informal feedback demonstrated active involvement. The CDA process involved an extra 80 person-days of time (40 from PPI co-researchers, 40 from academic researchers). The process was refined into a best practice framework comprising Preparation, CDA and Application phases. CONCLUSIONS: This study has developed a typology of approaches to collaborative analysis of qualitative data in mental health research, identified from available evidence the characteristics of successful involvement, and developed, piloted and refined the first best practice framework for collaborative analysis of qualitative data. This framework has the potential to support meaningful PPI in data analysis in the context of qualitative mental health research studies, a previously neglected yet central part of the research cycle.

Jones, A., Hannigan, B., Coffey, M., et al. (2018). "Traditions of research in community mental health care planning and care coordination: A systematic meta-narrative review of the literature." PLoS One **13**(6): e0198427.

> CONTEXT: In response to political and social factors over the last sixty years mental health systems internationally have endeavoured to transfer the delivery of care from hospitals into community settings. As a result, there has been increased emphasis on the need for better quality care planning and care coordination between hospital services, community services and patients and their informal carers. The aim of this systematic review of international research is to explore which interventions have proved more or less effective in promoting personalized, recovery oriented care planning and coordination for community mental health service users. METHODS: A systematic meta-narrative review of research from 1990 to the present was undertaken. From an initial return of 3940 papers a total of 50 research articles fulfilled the inclusion criteria, including research from the UK, Australia and the USA. FINDINGS: Three

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research traditions are identified consisting of (a) research that evaluates the effects of government policies on the organization, management and delivery of services; (b) evaluations of attempts to improve organizational and service delivery efficiency; (c) service-users and carers experiences of community mental health care coordination and planning and their involvement in research. The review found no seminal papers in terms of high citation rates, or papers that were consistently cited over time. The traditions of research in this topic area have formed reactively in response to frequent and often unpredictable policy changes, rather than proactively as a result of intrinsic academic or intellectual activity. This may explain the absence of seminal literature within the subject field. As a result, the research tradition within this specific area of mental health service delivery has a relatively short history, with no one dominant researcher or researchers, tradition or seminal studies amongst or across the three traditions identified. CONCLUSIONS: The research findings reviewed suggests a gap has existed internationally over several decades between policy aspirations and service level interventions aimed at improving personalised care planning and coordination and the realities of everyday practices and experiences of service users and carers. Substantial barriers to involvement are created through poor information exchange and insufficient opportunities for care negotiation.

Jørgensen, K. et Rendtorff, J. D. (2018). "Patient participation in mental health care - perspectives of healthcare professionals: an integrative review." Scand J Caring Sci **32**(2): 490-501.

BACKGROUND: In contemporary Western liberal society, patient participation has become a key goal in psychiatric healthcare treatment. Health professionals must encourage patients to play an active and involved part in their treatment. According to Danish health law, patients have the right to participate in their treatment, and the mental health system therefore needs to be reformed in order to ensure that treatment is based on individual, liberal, values. However, patient participation is not clearly defined, and it is therefore a challenge to transfer it to clinical practice. AIMS: This integrative review's aims are to explore how professionals perceive the challenges regarding patient participation in the treatment course in mental health care. DESIGN: An integrative review. FINDINGS: Seven studies met the inclusion criteria: six employed qualitative methodologies and one utilised a mixed-methods approach. The empirical studies took place in Norway, the UK and Australia, all in a mental health setting. Three themes were identified: 'Patient participation as collaboration between the healthcare professional and patient', 'Challenges to participation' and 'From a professional's perspective - what expectations do patients have when participating in decision-making?' CONCLUSION: Different synonymous terms describing the patient's active role during treatment - user participation, collaboration, partnership, user involvement and patient participation - are linked to a recovery-oriented approach, shared decision-making, shared ownership and care plans. This integrative review achieves specific knowledge around patient participation, comparing the situation for adult patients with various mental disorders. However, upon reflecting on the included studies, patient participation is not clearly defined, and it is therefore difficult to transfer it to clinical practice.

Kehayia, E., et al. (2017). "La santé, élément commun des politiques publiques ? L'expérience canadienne." Annales des Mines - Réalités industrielles **Mai 2017**(2): 85.
http://www.cairn.info/revue-realites-industrielles-2017-2-page-82.htm

Mené par le CRIR et ses partenaires, le projet Laboratoire Vivant de Réadaptation, RehabMaLL, collabore à la création d'un environnement facilitant la participation et l'inclusion des personnes

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de tous âges, particulièrement de celles vivant avec des incapacités physiques, dans un centre commercial du centre-ville de Montréal. Hormis le partenaire principal, FPI COMINAR, propriétaire du centre commercial, le projet inclut des milieux communautaires et associatifs, cliniques, le privé, ainsi que des chercheurs et des industriels locaux, nationaux et internationaux. Cette initiative découle de l'engagement actif et de la synergie entre des chercheurs et des partenaires qui se sont donné pour but de faire disparaître les obstacles créés par des environnements physiques et sociaux discriminants. Cette transformation se réalise au travers de solutions innovantes et de stratégies visant la réduction des inégalités et la promotion de l'accessibilité, du bien-être et, par conséquent, de la santé des Québécois.

Kendal, S. E., Milnes, L., Welsby, H., et al. (2017). "Prioritizing young people's emotional health support needs via participatory research." J Psychiatr Ment Health Nurs **24**(5): 263-271.

WHAT IS KNOWN ON THIS SUBJECT?: Young people's mental health is a concern to people around the world. Good emotional health promotes mental health and protects against mental illness, but we need to know more about how to help young people look after their emotional health. We are learning that research is better if the public are involved in it, including children and young people. Therefore, we need to listen carefully to what young people have to say. In this paper, we describe some research that involved young people from start to finish. We were asking what kind of emotional health support would be useful to them. WHAT THIS PAPER ADDS TO EXISTING KNOWLEDGE?: We developed a useful way to involve young people in research so their voice can be heard. Young people like to use the Internet to find emotional health support and information, but need to know which web sites they can trust. WHAT ARE THE IMPLICATIONS FOR PRACTICE?: Our method of bringing young people together to tell us their views was successful. It is important to explore ways to help young people judge the quality of emotional health web sites. ABSTRACT: Introduction Youth mental health is a global concern. Emotional health promotes mental health and protects against mental illness. Youth value self-care for emotional health, but we need better understanding of how to help them look after their emotional health. Participatory research is relevant, since meaningful engagement with youth via participatory research enhances the validity and relevance of research findings and supports young people's rights to involvement in decisions that concern them. Aim We aimed to develop a participatory approach for involving youth in research about their emotional health support preferences. Method Our team included a young expert-by-experience. We developed a qualitative, participatory research design. Eleven youth (16-18 years) participated in focus groups, followed immediately by a nominal group exercise in which they analysed the data, thus enhancing methodological rigour. Results This process highlighted youth perspectives on self-care strategies for emotional health. Discussion and implications for practice Our simple participatory research approach generated trustworthy and credible findings, which accurately reflect youth perspectives and are consistent with the literature, endorsing our method. Young people said that they want reassurances of quality and safety when accessing digital mental health resources. These findings can inform future development of youth-oriented digital mental health resources.

Kent, M. (2019). "Developing a Strategy to Embed Peer Support into Mental Health Systems." Adm Policy Ment Health **46**(3): 271-276.

Globally, health care systems stakeholders have encouraged health systems change that reflects recovery oriented practice. The implementation and integration of Peer Support Workers is one

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such strategy. Yet, what factors should be considered in the implementation of these roles? How can services be integrated effectively? Recent literature will be reviewed to explore current knowledge about peer support, and offer considerations for effective implementation of peer supports into current health care systems.

Kilcommons, A. M., et al. (2012). "Do service users with intellectual disabilities want to be involved in the risk management process? A thematic analysis." J Appl Res Intellect Disabil **25**(5): 433-444.

BACKGROUND: Involving ID service users in risk decision making necessitates consideration of an individual's ability to assess the implications and associated risks and thus make an informed choice. This calls for research on service users' awareness and understanding of risk management (RM). METHOD: Thirteen people in a residential ID service who were reviewed under the risk management process (RMP) participated in the research. Thematic analysis explored participants' knowledge and understanding of risk management to establish ability to make informed choice. RESULTS: Two main meta-themes (lack of awareness about RM and awareness about RM) and four meta-themes (extent of RM awareness, locus of control, compliance and empowerment) emerged. Nine of 13 participants demonstrated some knowledge and awareness of RM and wanted to contribute to the RMP, despite not being consulted about or given the opportunity to be involved in RM. CONCLUSIONS: The majority of service users in this sample had some awareness of the purpose of RM and could make partially informed decisions about whether they would like to be involved in the RMP. The findings highlight the need for professionals to actively attempt to involve ID service users in the management of their own risk.

Kim, M. et Lee, K. (2015). "[Development of Empowerment Program for Persons with Chronic Mental Illness and Evaluation of Impact]." J Korean Acad Nurs **45**(6): 834-845.

PURPOSE: This study was done to develop an empowerment program for people with chronic mental illness and to analyze effects of the program on level of empowerment. METHODS: The research was conducted using a nonequivalent control group pretest-posttest design. Participants were 37 people with chronic mental illness (experimental group: 18, control group: 19). The empowerment program was provided for 8 weeks (15 sessions). Data were collected between July 21 and October 17, 2014. Data were analyzed using Chi-square, Fisher's exact test, Sapiro-Wilk test, and Repeated measure ANOVA with SPSS/WIN 18.0. RESULTS: Quantitative results show that self-efficacy, interpersonal relationships, attitudes in the workplace, occupational performance capacity, and levels of empowered execute were significantly better in the experimental group compared to the control group. CONCLUSION: Study findings indicate that this empowerment program for persons with chronic mental illness is effective for improving self efficacy, interpersonal skills, attitudes in the workplace, occupational performance capacity, levels of empowered execute.

Knightbridge, S. M., et al. (2006). "Using participatory action research in a community-based initiative addressing complex mental health needs." Australian and New Zealand Journal of Psychiatry **40**(4): 325-332.

Kortteisto, T., Laitila, M. et Pitkänen, A. (2018). "Attitudes of mental health professionals towards service user involvement." Scand J Caring Sci **32**(2): 681-689.

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Patient-centred care and user involvement in healthcare services are much emphasised globally. This study was the first step in a multicentre research project in Finland to improve service users' and carers' opportunities to be more involved in mental health services. The aim of the study was to assess attitudes of professionals towards service user involvement. The data were collected via an online questionnaire from 1069 mental health professionals in four hospital districts. Altogether, 351 professionals responded. Data were analysed using appropriate statistical methods. According to the results, attitudes of healthcare professionals were more positive towards service users' involvement in their own treatment than in other levels of services. There were also differences in gender, age groups, working places and experiences in the attitudes of professionals concerning service users' involvement in their own treatment. These should be taken into account in the future when planning education for mental health professionals. In spite of governmental guidance on service user involvement and the growing body of knowledge of the benefits associated with it, change in attitudes towards user involvement is slow. Special attention should be paid to the attitudes of professionals working in inpatient care and of those with less working experience.

Krotofil, J., McPherson, P. et Killaspy, H. (2018). "Service user experiences of specialist mental health supported accommodation: A systematic review of qualitative studies and narrative synthesis." Health Soc Care Community **26**(6): 787-800.

Specialist supported accommodation services have become a key component of most community-based mental healthcare systems. While mental health policies highlight the importance of service user involvement in service development and care planning, there are no comprehensive literature reviews synthesising services users' perspectives on, or experiences of, supported accommodation services. This systematic review was undertaken to fill this gap. We searched electronic databases (January 2015, updated June 2017), conducted hand searches and used forward-backward snowballing to identify 13,678 papers. We inspected the full-text of 110 papers and included 50 of these in the final review. Data extraction and quality assessments were conducted. We used narrative synthesis to develop a conceptual model of service users' experiences that included structural, process, relational and contextual factors, such as the characteristics of the service, relationships with staff and other service users, the intensity and nature of support, the physical environment, and social and community integration. The review highlights the complex interplay of individual, service-level and community factors in shaping the lived experience of service users and their impact on personal identity and recovery. Our approach addressed some of the widely reported limitations of the quantitative research in this field, providing a conceptual model relevant to service user experiences across supported accommodation service types, population groups and countries.

Laditka, J. N., et al. (2009). "Promoting cognitive health: a formative research collaboration of the healthy aging research network." Gerontologist **49 Suppl 1**: S12-17.

PURPOSE: Evidence suggests that healthy lifestyles may help maintain cognitive health. The Prevention Research Centers Healthy Aging Research Network, 9 universities collaborating with their communities and the Centers for Disease Control and Prevention, is conducting a multiyear research project, begun in 2005, to understand how to translate this knowledge into public health interventions. DESIGN AND METHODS: This article provides an overview of the study purpose, design, methods, and processes. We examined the literature on promoting cognitive health, convened a meeting of experts in cognitive health and public health interventions,

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identified research questions, developed a common focus group protocol and survey, established quality control and quality assurance processes, conducted focus groups, and analyzed the resulting data. RESULTS: We conducted 55 focus groups with 450 participants in 2005-2007, and an additional 20 focus groups and in-depth interviews in 2007-2008. Focus groups were in English, Spanish, Mandarin, Cantonese, and Vietnamese, with African Americans, American Indians, Asian Americans, Hispanics, non-Hispanic Whites, physicians and other health practitioners, rural and urban residents, individuals caring for family or friends with cognitive impairment, and cognitively impaired individuals. IMPLICATIONS: The data provide a wealth of opportunities for designing public health interventions to promote cognitive health in diverse populations.

Laitila, M., Nummelin, J., Kortteisto, T., et al. (2018). "Service users' views regarding user involvement in mental health services: A qualitative study." Arch Psychiatr Nurs **32**(5): 695-701.

BACKGROUND: Service user involvement is emphasised in many strategies, plans and declarations globally. However, in practice, service user involvement is not always achieved and remains at a tokenistic level. OBJECTIVES: To explore the views of service users on user involvement in mental health service. DESIGN: Explorative descriptive study design. SETTING: The study was conducted in one psychiatric hospital and in two mental health organisations in western Finland. METHODS: The data was generated through three focus group interviews and analysed with qualitative content analysis. RESULTS: User involvement means that people using mental health services are respected, listened to and can act in co-operation with professionals so than they feel that they can influence their own care and treatment. The participants articulated concrete factors that promote or inhibit user involvement. Service user involvement can be enhanced by strengthening service users´ position, by developing the mental health care system and by specific training for professionals. CONCLUSIONS: The views of service users in this study concerning the realisation of user involvement and the factors promoting and preventing it were realistic. They are basic elements of patient-centred care and of all human interaction. Our participants described service user involvement in their own care and treatment. They emphasised the need to have more information, and wanted to be more involved in decision-making about their own care and treatment. They called for better care planning and co-ordination as one way to increase service user involvement. These also have implications for mental health services at the system level.

Lean, M., Fornells-Ambrojo, M., Milton, A., et al. (2019). "Self-management interventions for people with severe mental illness: systematic review and meta-analysis." Br J Psychiatry **214**(5): 260-268.

BACKGROUND: Self-management is intended to empower individuals in their recovery by providing the skills and confidence they need to take active steps in recognising and managing their own health problems. Evidence supports such interventions in a range of long-term physical health conditions, but a recent systematic synthesis is not available for people with severe mental health problems.AimsTo evaluate the effectiveness of self-management interventions for adults with severe mental illness (SMI). METHOD: A systematic review of randomised controlled trials was conducted. A meta-analysis of symptomatic, relapse, recovery, functioning and quality of life outcomes was conducted, using RevMan. RESULTS: A total of 37 trials were included with 5790 participants. From the meta-analysis, self-management interventions conferred benefits in terms of reducing symptoms and length of admission, and improving functioning and quality of life both at the end of treatment and at follow-up. Overall

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the effect size was small to medium. The evidence for self-management interventions on readmissions was mixed. However, self-management did have a significant effect compared with control on subjective measures of recovery such as hope and empowerment at follow-up, and self-rated recovery and self-efficacy at both time points. CONCLUSION: There is evidence that the provision of self-management interventions alongside standard care improves outcomes for people with SMI. Self-management interventions should form part of the standard package of care provided to people with SMI and should be prioritised in guidelines: research on best methods of implementing such interventions in routine practice is needed.Declaration of interestsNone.

Levac, L., Ronis, S., Cowper-Smith, Y., et al. (2019). "A scoping review: The utility of participatory research approaches in psychology." J Community Psychol **47**(8): 1865-1892.

Consistent with community psychology's focus on addressing societal problems by accurately and comprehensively capturing individuals' relationships in broader contexts, participatory research approaches aim to incorporate individuals' voices and knowledge into understanding, and responding to challenges and opportunities facing them and their communities. Although investigators in psychology have engaged in participatory research, overall, these approaches have been underutilized. The purpose of this review was to examine areas of research focus that have included participatory research methods and, in turn, highlight the strengths and ways that such methods could be better used by researchers. Nearly 750 articles about research with Indigenous Peoples, children/adolescents, forensic populations, people with HIV/AIDS, older adults, and in the area of industrial-organizational psychology were coded for their use of participatory research principles across all research stages (i.e., research design, participant recruitment and data collection, analysis and interpretation of results, and dissemination). Although we found few examples of studies that were fully committed to participatory approaches to research, and notable challenges with applying and reporting on this type of work, many investigators have developed creative ways to engage respectfully and reciprocally with participants. Based on our findings, recommendations and suggestions for researchers are discussed.

Liegghio, M., et al. (2010). "Partnering with children diagnosed with mental health issues: contributions of a sociology of childhood perspective to participatory action research." Am J Community Psychol **46**(1-2): 84-99.

This paper explores the use of participatory action research (PAR) with children diagnosed with mental health issues. We argue that critiques from the sociology of childhood are useful for guiding PAR with children. First, we describe and critique values and assumptions that underlie research and practice with children who experience mental health issues. Second, we outline key qualities of the sociology of childhood, discuss their implications for PAR with children diagnosed with mental health issues, and touch on ethical issues. Five themes are explored: (a) values, (b) ontology/epistemology, (c) views about children, (d) agency/power in children's relationships with adults, and (e) intervention/change focus. We conclude by encouraging community psychologists to consider PAR with children diagnosed with mental health issues.

Lizaola, E., et al. (2011). "The Partnered Research Center for Quality Care: developing infrastructure to support community-partnered participatory research in mental health." Ethn Dis **21**(3 Suppl 1): S1-58-70.

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Evidence-based programs have been shown to improve functioning and mental health outcomes, especially for vulnerable populations. However, these populations face numerous barriers to accessing care including lack of resources and stigma surrounding mental health issues. In order to improve mental health outcomes and reduce health disparities, it is essential to identify methods for reaching such populations with unmet need. A promising strategy for reducing barriers and improving access to care is Community Partnered Participatory Research (CPPR). Given the power of this methodology to transform the impact of research in resource-poor communities, we developed an NIMH-funded Center, the Partnered Research Center for Quality Care, to support partnerships in developing, implementing, and evaluating mental health services research and programs. Guided by a CPPR framework, center investigators, both community and academic, collaborate in all phases of research with the goal of establishing trust, building capacity, increasing buy-in, and improving the sustainability of interventions and programs. We engage in two-way capacity-building, which affords the opportunity for practical problems to be raised and innovative solutions to be developed. This article discusses the development and design of the Partnered Research Center for Quality Care and provides examples of partnerships that have been formed and the work that has been conducted as a result.

Luisi, D. et Hämel, K. (2021). "Community participation and empowerment in primary health care in Emilia-Romagna: A document analysis study." Health policy **125**(2): 177-184.
https://doi.org/10.1016/j.healthpol.2020.11.007

Community participation and empowerment are seen as fundamental for achieving equitable, people-centred primary health care. Emilia-Romagna region introduced the Casa della Salute aiming to foster comprehensive primary health care and support community participation. Since the 1990s, community involvement has been promoted to improve the regional health system. The pivotal role of third sector organisations as service providers and advocates for users' rights has been underlined. This contribution explores the evolution of the meaning and conceptualisation of community participation and empowerment in policies addressing the Casa della Salute. A qualitative document analysis study was undertaken. Three national and twelve regional documents dated between 2006 and 2019 were evaluated. The policies continuously address community participation. The Casa della Salute is seen as a designated place to promote participation and empowerment. The documents point to the need for democratic practice and shared decision-making power; third sector organisations are seen as salient community representatives and mediators. However, the policies show only a vague conceptualisation of how to empower communities; moreover, strategies to promote participation of vulnerable groups are lacking. Policies that consider the ambiguous role of the third sector, specify community empowerment, identify strategies to facilitate it and collaborate with vulnerable groups could be beneficial for further progress.

MacInnes, D., et al. (2011). "Service-user involvement in forensic mental health care research: areas to consider when developing a collaborative study." J Ment Health **20**(5): 464-472.

BACKGROUND: Although service-users are increasingly involved in the conduct of research in mental health settings, involvement in forensic mental health settings is limited. AIMS: This paper looks at the factors perceived by professionals and service-users as important for developing collaborative research in forensic mental health settings. METHOD: Following a

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collaborative research project undertaken in three forensic mental health units, the researchers involved in the project (professionals and service-users) reviewed factors perceived as important for developing service-user research in secure settings. RESULTS: Three broad themes were identified. The main issues considered within these themes were detailed. CONCLUSIONS: Service-users in forensic mental health settings are able to have full involvement in research.

Luisi, D. et Hämel, K. (2021). "Community participation and empowerment in primary health care in Emilia-Romagna: A document analysis study." Health policy **125**(2): 177-184.
https://doi.org/10.1016/j.healthpol.2020.11.007

Community participation and empowerment are seen as fundamental for achieving equitable, people-centred primary health care. Emilia-Romagna region introduced the Casa della Salute aiming to foster comprehensive primary health care and support community participation. Since the 1990s, community involvement has been promoted to improve the regional health system. The pivotal role of third sector organisations as service providers and advocates for users' rights has been underlined. This contribution explores the evolution of the meaning and conceptualisation of community participation and empowerment in policies addressing the Casa della Salute. A qualitative document analysis study was undertaken. Three national and twelve regional documents dated between 2006 and 2019 were evaluated. The policies continuously address community participation. The Casa della Salute is seen as a designated place to promote participation and empowerment. The documents point to the need for democratic practice and shared decision-making power; third sector organisations are seen as salient community representatives and mediators. However, the policies show only a vague conceptualisation of how to empower communities; moreover, strategies to promote participation of vulnerable groups are lacking. Policies that consider the ambiguous role of the third sector, specify community empowerment, identify strategies to facilitate it and collaborate with vulnerable groups could be beneficial for further progress.

Maciver, D., et al. (2013). "Vocational rehabilitation: facilitating evidence based practice through participatory action research." J Ment Health **22**(2): 183-190.

BACKGROUND: Improving vocational rehabilitation in line with the current evidence base is an area of considerable interest. Aims To describe the strategies used by a multidisciplinary team in the initial stages of a participatory action research (PAR) approach to improving a vocational rehabilitation service. METHOD: A literature review and PAR process were completed. One hundred and fifteen participants engaged in multifaceted data collection and analysis, building consensus around key principles for a new vocational rehabilitation service. RESULTS: A synthesis of our literature review and PAR process was developed into a set of principles for practice which we plan to implement across the service. CONCLUSIONS: We have developed methodologies in interdisciplinary collaborations spanning statutory and non-statutory services. We have developed a set of principles for practice and detailed plans for implementation are being drawn up to inform provision in the future.

Mahone, I. H., Farrell, S. P., Hinton, I., et al. (2011). "Participatory Action Research in Public Mental Health and a School of Nursing: Qualitative Findings from an Academic-Community Partnership." Journal of participatory medicine **3**: e-10.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3234528/

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An academic-community partnership between a school of nursing (SON) at a public university (the University of Virginia, or UVA) and a public mental health clinic developed around a shared goal of finding an acceptable shared decision making (SDM) intervention targeting medication use by persons with serious mental illness. The planning meetings of the academic-community partnership were recorded and analyzed. Issues under the partnership process included 1) clinic values and priorities, 2) research agenda, 3) ground rules, and 4) communication. Issues under the SDM content included: 1) barriers, 2) information exchange, 3) positive aspects of shared decision making, and 4) technology. Using participatory-action research (PAR), the community clinic was able to raise questions and concerns throughout the process, be actively involved in research activities (such as identifying stakeholders and co-leading focus groups), participate in the reflective activities on the impact of SDM on practice and policy, and feel ownership of the SDM intervention.

Mahlke, C., Schulz, G., Sielaff, G., et al. (2019). "[Models of peer support in psychiatric care]." Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz **62**(2): 214-221.

In the past decades, psychiatric care has changed from the traditional medical model to a more person-centered and recovery-focused approach. In this process, peer support workers are essential, because with their lived experience of crisis and recovery they are able to spread hope.This article gives an overview of the recent literature describing the current change model of peer support, reporting the evidence of peer support, as well as the current stage of implementation of peer support in different psychiatric contexts.An overview of the current state of research, selected by the authors, based on repeated systematic literature searches in peer support research projects, is given. Additionally, some examples of user involvement from the Hamburg EX-IN Curriculum, trialogs between sufferers, relatives and professionals, as well as the so-called psychosis seminars are described in more detail.Peer support has shown promising results in one-to-one and group settings, case management, crisis interventions, and the reduction of coercive measures.Although there are promising results of peer support in various clinical contexts, multiple challenges in the implementation of peer support are reported. They need to be overcome by the inclusion of all staff members in the change process of the system in order to further develop user-oriented and recovery-oriented psychiatric care.

McGowan, V. J., Wistow, J., Lewis, S. J., et al. (2019). "Pathways to mental health improvement in a community-led area-based empowerment initiative: evidence from the Big Local 'Communities in Control' study, England." J Public Health (Oxf) **41**(4): 850-857.

BACKGROUND: Area-based initiatives that include a focus on community empowerment are increasingly being seen as potentially an important way of improving health and reducing inequalities. However, there is little empirical evidence on the pathways between communities having more control and health outcomes. PURPOSE: To identify pathways to health improvement in a community-led area-based community empowerment initiative. METHODS: Longitudinal data on mental health, community control, area belonging, satisfaction, social cohesion and safety were collected over two time points, 6 months apart from 48 participants engaged in the Big Local programme, England. Qualitative comparative analysis (QCA) was used to explore pathways to health improvement. RESULTS: There was no clear single pathway that led to mental health improvement but positive changes in 'neighbourhood belonging' featured in 4/5 health improvement configurations. Further, where respondents experienced no improvement in key social participation/control factors, they experienced no health

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improvement. CONCLUSION: This study demonstrates a potential pathway between an improvement in 'neighbourhood belonging' and improved mental health outcomes in a community empowerment initiative. Increasing neighbourhood belonging could be a key target for mental health improvement interventions.

Mance, G. A., et al. (2010). "Utilizing community-based participatory research to adapt a mental health intervention for African American emerging adults." Progress in community health partnerships: research, education, and action **4**(2): 131-140.

Martin, S., et al. (2013). "Participatory research to design a novel telehealth system to support the night-time needs of people with dementia: NOCTURNAL." Int J Environ Res Public Health **10**(12): 6764-6782.

> Strategies to support people living with dementia are broad in scope, proposing both pharmacological and non-pharmacological interventions as part of the care pathway. Assistive technologies form part of this offering as both stand-alone devices to support particular tasks and the more complex offering of the "smart home" to underpin ambient assisted living. This paper presents a technology-based system, which expands on the smart home architecture, orientated to support people with daily living. The system, NOCTURNAL, was developed by working directly with people who had dementia, and their carers using qualitative research methods. The research focused primarily on the nighttime needs of people living with dementia in real home settings. Eight people with dementia had the final prototype system installed for a three month evaluation at home. Disturbed sleep patterns, night-time wandering were a focus of this research not only in terms of detection by commercially available technology but also exploring if automated music, light and visual personalized photographs would be soothing to participants during the hours of darkness. The NOCTURNAL platform and associated services was informed by strong user engagement of people with dementia and the service providers who care for them. NOCTURNAL emerged as a holistic service offering a personalised therapeutic aspect with interactive capabilities.

Mayer, G., et al. (2012). "Repetitive transcranial magnetic stimulation in depressed adolescents: experience, knowledge, and attitudes of recipients and their parents." J ect **28**(2): 104-107.

> BACKGROUND: Comprehensive assessment of new treatments in psychiatry should include evaluation of their acceptability to patients, and in the case of children and adolescents, this must extend to acceptability for parents. The views of young patients and their parents in relation to repetitive transcranial magnetic stimulation (rTMS) for adolescent depression have not been previously studied. OBJECTIVE: We sought to (1) describe the experience, knowledge, and attitudes regarding rTMS among young people who had been treated with rTMS for depression as adolescents; (2) report the views of their parents; and (3) compare these to opinions about pharmacotherapy among a group who had been treated with fluoxetine for adolescent depression. METHODS: Eight of 9 subjects who had participated in an open-label rTMS study, 13 of their parents, and an age-matched group of 8 subjects who had been treated with fluoxetine for depression as adolescents were assessed using detailed questionnaires. RESULTS: Repetitive TMS recipients and their parents found rTMS largely acceptable in terms of adverse effects and treatment experience, but most considered it ineffective. In contrast, most patients who had been treated with fluoxetine viewed their treatment as effective. CONCLUSIONS: Transcranial magnetic stimulation is relatively well tolerated by depressed adolescents, but it is also perceived as mostly unhelpful by them and their parents. This is at

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odds with emerging studies suggesting that rTMS can be an effective and safe treatment in this age group, indicating that further research is required to confirm our findings and understand reasons for any disparity.

McCauley, C. O., McKenna, H., Keeney, S., et al. (2017). "Service user engagement: A co-created interview schedule exploring mental health recovery in young adults." J Adv Nurs **73**(10): 2361-2372.

> AIM: The aim of this study was to co-create of an interview schedule exploring mental health recovery in collaboration with young adult service users. BACKGROUND: Service user involvement in research has been increasingly recognized as providing a vital authentic insight into mental health recovery. Engagement and collaboration with service users have facilitated the exploration of inaccessible or under-investigated aspects of the lived experience of mental health recovery, not only directing the trajectory of research, but making it relevant to their own contextual experience. DESIGN: A qualitative content analysis framework was employed in the co-creation of a semi-structured interview schedule through an engagement process with service users. METHODS: Two separate engagement groups took place at the premises of the service user organizations, between January - February 2014. Miles and Huberman's analysis framework was chosen for this phase as it enabled the visual presentation of factors, concepts or variables and the established relationship between them. RESULTS: The lived experience of mental ill health in young adulthood and how this was understood by others was a particularly relevant theme for participants. Further themes were identified between the impact of painful experiences at this developmental life stage leading to a deeper understanding of others through finding meaning in their own mental health recovery journey. CONCLUSION: Our findings identified that suffering painful experiences is an integral aspect in the process of mental health recovery. This understanding has particular relevance to mental health nursing practice, ensuring the care delivered is cognizant of the suffering or painful experiences that young adults are encountering.

McDaid, S. (2009). "An equality of condition framework for user involvement in mental health policy and planning: evidence from participatory action research." Disability & Society **24**(4): 461-474.

Mendel, P., et al. (2008). "Interventions in organizational and community context: a framework for building evidence on dissemination and implementation in health services research." Administration and Policy in Mental Health and Mental Health Services Research **35**(1-2): 21-37.

Michaelis, S., Kriston, L., Harter, M., et al. (2017). "Predicting the preferences for involvement in medical decision making among patients with mental disorders." PLoS One **12**(8): e0182203.

> BACKGROUND: The involvement of patients in medical decision making has been investigated widely in somatic diseases. However, little is known about the preferences for involvement and variables that could predict these preferences in patients with mental disorders. OBJECTIVE: This study aims to determine what roles mentally ill patients actually want to assume when making medical decisions and to identify the variables that could predict this role, including patients' self-efficacy. METHOD: Demographic and clinical data of 798 patients with mental disorders from three psychotherapeutic units in Germany were elicited using self-report questionnaires. Control preference was measured using the Control Preferences Scale, and patients' perceived self-efficacy was assessed using the Self-Efficacy Scale. Bivariate and multivariate regression analyses were conducted to investigate the associations between patient variables and control

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preference. RESULTS: Most patients preferred a collaborative role (57.5%), followed by a semi passive (21.2%), a partly autonomous (16.2%), an autonomous (2.8%) and a fully passive (2.3%) role when making medical decisions. Age, sex, diagnosis, employment status, medical pretreatment and perceived self-efficacy were associated with the preference for involvement in the multivariate logistic model. CONCLUSION: Our results confirm the preferences for involvement in medical decisions of mentally ill patients. We reconfirmed previous findings that older patients prefer a shared role over an autonomous role and that subjects with a high qualification prefer a more autonomous role over a shared role. The knowledge about predictors may help strengthen treatment effectiveness because matching the preferred and actual role preferences has been shown to improve clinical outcome.

Moltu, C., et al. (2012). "Negotiating the coresearcher mandate - service users' experiences of doing collaborative research on mental health." Disabil Rehabil **34**(19): 1608-1616.

PURPOSE: Traditionally, the voices of service users have been silent in research into mental health issues. A Norwegian research network, however, recognizes the importance of involving service users as coresearchers and initiated a training program in research methodology and design intended to empower them as active participants in research projects. In this article, we explore how these coresearchers with a mental health service user background experience their participation in projects as well as in attending the training: What is it like being a service user coresearcher in collaborative studies on issues in mental health? How do coresearchers negotiate their roles and mandate? METHOD: We used focus groups as our data collection method, transcribed the group discussions verbatim, and analyzed the transcriptions using qualitative methodology. We then took the preliminary analyses back to the participants for discussion, auditing, and reanalysis. RESULTS: We identified themes that represent important social processes around which the participants developed a consensual understanding: self-definition, constructive differentiation and negotiations. CONCLUSION: Our findings generate hypotheses on how participatory research into mental health issues can be fruitfully organized, in a way that empowers service users to active and constructive participation.

Moreno-Poyato, A. R., Delgado-Hito, P., Suarez-Perez, R., et al. (2018). "Improving the therapeutic relationship in inpatient psychiatric care: Assessment of the therapeutic alliance and empathy after implementing evidence-based practices resulting from participatory action research." Perspect Psychiatr Care **54**(2): 300-308.

PURPOSE: To examine how evidence about the therapeutic alliance gleaned from participatory action project affected the level of this alliance and the degree of empathy of psychiatric nurses. DESIGN AND METHODS: Quasi-experimental study in two psychiatric units. In one group, evidence-based practices that affected the therapeutic alliance were implemented; in the comparison group, there was no such intervention. FINDINGS: The nurses from the intervention group improved their degree of empathy and factors such as agreement on objectives and tasks with the patient. PRACTICE IMPLICATIONS: The results confirm the possibility of measuring and improving the therapeutic relationship in psychiatric care.

Mpango, R., Kalha, J., Shamba, D., et al. (2020). "Challenges to peer support in low- and middle-income countries during COVID-19." Global Health **16**(1): 90.

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BACKGROUND: A recent editorial urged those working in global mental health to "change the conversation" on coronavirus disease (Covid-19) by putting more focus on the needs of people with severe mental health conditions. UPSIDES (Using Peer Support In Developing Empowering mental health Services) is a six-country consortium carrying out implementation research on peer support for people with severe mental health conditions in high- (Germany, Israel), lower middle- (India) and low-income (Tanzania, Uganda) settings. This commentary briefly outlines some of the key challenges faced by UPSIDES sites in low- and middle-income countries as a result of Covid-19, sharing early lessons that may also apply to other services seeking to address the needs of people with severe mental health conditions in similar contexts. CHALLENGES AND LESSONS LEARNED: The key take-away from experiences in India, Tanzania and Uganda is that inequalities in terms of access to mobile technologies, as well as to secure employment and benefits, put peer support workers in particularly vulnerable situations precisely when they and their peers are also at their most isolated. Establishing more resilient peer support services requires attention to the already precarious situation of people with severe mental health conditions in low-resource settings, even before a crisis like Covid-19 occurs. While it is essential to maintain contact with peer support workers and peers to whatever extent is possible remotely, alternatives to face-to-face delivery of psychosocial interventions are not always straightforward to implement and can make it more difficult to observe individuals' reactions, talk about emotional issues and offer appropriate support. CONCLUSIONS: In environments where mental health care was already heavily medicalized and mostly limited to medications issued by psychiatric institutions, Covid-19 threatens burgeoning efforts to pursue a more holistic and person-centered model of care for people with severe mental health conditions. As countries emerge from lockdown, those working in global mental health will need to redouble their efforts not only to make up for lost time and help individuals cope with the added stressors of Covid-19 in their communities, but also to regain lost ground in mental health care reform and in broader conversations about mental health in low-resource settings.

Mulvale, G., Wilson, F., Jones, S., et al. (2019). "Integrating mental health peer support in clinical settings: Lessons from Canada and Norway." Healthc Manage Forum **32**(2): 68-72.

Mental health peer support is an evidence-based approach called for by Canada's mental health strategy that presents health leaders with an opportunity to transform mental health service experiences, improve health outcomes, and lower overall system costs. Originally offered in community settings, peer support has been expanding to clinical settings, but challenges to integration exist. This qualitative case study of peer support in clinical settings in Canada and Norway examines the perceived value of peer support and change management strategies that health leaders, managers, staff, and peer support providers can use to support integration of peer support in existing healthcare teams in clinical settings. Recommended strategies for health leaders include adopting a gradual approach to integration, building champions, demonstrating value, focusing on resistant groups, adopting a continuous improvement approach, setting peer support as an organizational priority, and linking peer support to patient-centred care.

Muzik, M., et al. (2016). "Teenage mothers of black and minority ethnic origin want access to a range of mental and physical health support: a participatory research approach." Health Expect **19**(2): 403-415.

BACKGROUND: In high risk, economically disadvantaged neighbourhoods, such as those primarily resident by black and minority ethnic groups (BME), teenage pregnancies are relatively

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more frequent. Such families often have limited access to and/or knowledge of services, including prenatal and post-partum physical and mental health support. OBJECTIVE: To explore preferences held by vulnerable young mothers of BME origin and those close to them about existing and desired perinatal health services. DESIGN, SETTING AND PARTICIPANTS: Drawing on a community-based participatory approach, a community steering committee with local knowledge and experience of teenage parenthood shaped and managed an exploratory qualitative study. In collaboration with a local agency and academic research staff, community research assistants conducted two focus groups with 19 members and 21 individual semi-structured interviews with young mothers of BME origin and their friends or relatives. These were coded, thematically analysed, interpreted and subsequently triangulated through facilitator and participant review and discussion. RESULTS: Despite perceptions of a prevalent local culture of mistrust and suspicion, a number of themes and accompanying recommendations emerged. These included a lack of awareness by mothers of BME origin about current perinatal health services, as well as programme inaccessibility and inadequacy. There was a desire to engage with a continuum of comprehensive and well-publicized, family-focused perinatal health services. Participants wanted inclusion of maternal mental health and parenting support that addressed the whole family. CONCLUSIONS: It is both ethical and equitable that comprehensive perinatal services are planned and developed following consultation and participation of knowledgeable community members including young mothers of BME origin, family and friends.

Nelson, G., et al. (1998). ""Nothing About Me, Without Me": Participatory Action Research with Self-Help/Mutual Aid Organizations for Psychiatric Consumer/Survivors." Am J Community Psychol **26**(6): 881-912.

Nicolaidis, C., et al. (2015). "Community-Based Participatory Research to Adapt Health Measures for Use by People With Developmental Disabilities." Prog Community Health Partnersh **9**(2): 157-170.

BACKGROUND: People with developmental disabilities (DD) are often not included as participants in research owing to a variety of ethical and practical challenges. One major challenge is that traditional measurement instruments may not be accessible to people with DD. Participatory research approaches promise to increase the participation of marginalized communities in research, but few partnerships have successfully used such approaches to conduct quantitative studies people with DD. OBJECTIVE: To use a community-based participatory research (CBPR) approach to create an accessible, computer-assisted survey about violence and health in people with DD, and to psychometrically test adapted health instruments. METHODS: Our academic-community partnership, composed of academic researchers, people with DD, and supporters, collaboratively selected and modified data collection instruments, conducted cognitive interviews and pilot tests, and then administered the full survey to 350 people with DD. RESULTS: Although team members sometimes had opposing accommodation needs and adaptation recommendations, academic and community partners were able to work together successfully to adapt instruments to be accessible to participants with a wide range of DD. Results suggest the adapted health instruments had strong content validity and all but one had good to excellent internal consistency reliability (alpha, 0.81-0.94). The majority of participants (75%) responded that all or most of the questions were easy to understand. CONCLUSIONS: Researchers should consider using participatory approaches to adapting instruments so people with DD can be validly included in research.

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Nierse, C. J. et Abma, T. A. (2011). "Developing voice and empowerment: the first step towards a broad consultation in research agenda setting." J Intellect Disabil Res **55**(4): 411-421.

> BACKGROUND: Although people with intellectual disabilities (ID) are increasingly consulted in research, participation in research agenda setting processes is limited. This is not surprising as their voice can easily be dominated in consultations with researchers. The aim of this article is to explore the potentials of enclave deliberation as a first step towards broad consultation in research agenda setting. METHOD: The research agenda setting process followed a responsive methodology, which is characterised by a cyclical and emergent design. Two persons with ID and one parent participated in the research team. Seven persons with ID and six parents were interviewed individually. Subsequently, 10 focus groups were organised with people with ID and four focus groups with parents. Also, a questionnaire was sent to parents. RESULTS: The process towards involvement of people with ID was characterised by several steps that guided enclave deliberation. First, stories of people were collected that reflected their intimate voice. Then, a political voice was further developed through dialogue and interaction in focus groups. This process resulted in a prioritised list of nine potential topics for research. CONCLUSION: The process of developing intimate voice and political voice can be regarded as a concretisation of enclave deliberation among disempowered groups. These steps are necessary to initiate a process towards establishing a broad consultation between different stakeholders about research on ID.

Nomura, M., et al. (2009). "Empowering older people with early dementia and family caregivers: a participatory action research study." Int J Nurs Stud **46**(4): 431-441.

> BACKGROUND: The increase in the number of people suffering from dementia is of increasing global concern. A survey on the living conditions of the elderly in a Japanese rural community revealed a high prevalence of early dementia and the necessity for interventions not only for the elderly with early dementia but also for their families. OBJECTIVE: To describe the implementation and process evaluation of a programme based on cognitive rehabilitation aimed at empowering the elderly with early dementia and education and counselling programmes aimed at likewise empowering their family caregivers. DESIGN: This study used a community health action research model. Participatory action research (PAR) was conducted through a cycle of planning, action, and reflection to identify effective interventions to empower participants with dementia (PsWD) and their caregivers. SETTING: A rural town in Japan. PARTICIPANTS: This project involved 37 community-dwelling elderly with early or mild dementia and 31 family caregivers. METHODS: A focus group interview was used for assessment. A monthly activity-based programme based on cognitive rehabilitation was developed to improve cognitive function. Three types of data were collected: observational data collected during the activities, written comments from the caregivers, the record of phone interviews and counsellings with caregivers. These data were compiled in chronological order into a portfolio for analysis. To empower family caregivers, educational and counselling programmes were offered. RESULTS: The PAR lasted for 5 years and evolved over three cycles: individual, group and community. In the first cycle, the major focus of the intervention was to regain procedural skills for each PWD through a cooking programme. In the second cycle, to increase interactions with family members and with other PsWD, group activities that promoted communication among family members as well as among PsWD were implemented. The collective values and the beliefs of the PsWD's generation were validated by a series of trips to temples and shrines. In the third cycle, community participation was planned and implemented through culturally

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relevant sequential activities. PsWD demonstrated their expert skills and regained confidence. For family caregivers, the educational programme provided knowledge about dementia and utilization of social resources. Face-to-face and phone counsellings were offered as needed to coach problem-focused coping. These programmes helped to interpret the symptoms of dementia and to reduce the behavioural problems. CONCLUSIONS: Cognitive rehabilitation theory was useful to restore lost procedural skills and regain confidence for PsWD. This PAR illustrated the importance of interventions for both community dwelling elderly with early dementia and their family caregivers.

Ochocka, J., et al. (2002). "Sharing power and knowledge: professional and mental health consumer/survivor researchers working together in a participatory action research project." Psychiatr Rehabil J **25**(4): 379.

Omer, S., et al. (2016). "Exploring the Mechanisms of a Patient-Centred Assessment with a Solution Focused Approach (DIALOG+) in the Community Treatment of Patients with Psychosis: A Process Evaluation within a Cluster-Randomised Controlled Trial." PLoS One **11**(2): e0148415.

BACKGROUND: DIALOG+ is a new intervention to make routine community mental health meetings therapeutically effective. It involves a structured assessment of patient concerns and a solution-focused approach to address them. In a randomised controlled trial, DIALOG+ was associated with better subjective quality of life and other outcomes in patients with psychosis, but it was not clear how this was achieved. This study explored the possible mechanisms. METHODS: This was a mixed-methods process evaluation within a cluster-randomised controlled trial. Focus groups and interviews were conducted with patients and clinicians who experienced DIALOG+ and were analysed using thematic analysis. The content of DIALOG+ sessions was recorded and analysed according to (i) the type of actions agreed during sessions and (ii) the domains discussed. The subjective quality of life measure was analysed with mixed-effects models to explore whether the effect of DIALOG+ was limited to life domains that had been addressed in sessions or consistent across all domains. RESULTS: Four qualitative themes emerged regarding the mechanisms of DIALOG+: (1) a comprehensive structure; (2) self-reflection; (3) therapeutic self-expression; and (4) empowerment. Patients took responsibility for the majority of actions agreed during sessions (65%). The treatment effect on subjective quality of life was largest for living situation (accommodation and people that the patient lives with) and mental health. Two of these domains were among the three most commonly discussed in DIALOG+ sessions (accommodation, mental health, and physical health). CONCLUSION: DIALOG+ initiates positive, domain-specific change in the areas that are addressed in sessions. It provides a comprehensive and solution-focused structure to routine meetings, encourages self-reflection and expression, and empowers patients. Future research should strengthen and monitor these factors. TRIAL REGISTRATION: ISRCTN Registry ISRCTN34757603.

Passos, E., et al. (2013). "[The Citizen Committee as a co-management strategy in participatory research in the field of mental health in Quebec]." Cien Saude Colet **18**(10): 2919-2928.

The theme of users' rights has become a central issue in contemporary debate on mental health. Drawing from the experiences of "Comite Cidadao" (Citizen Committee), consisting of users and family members in an international research alliance between Brazil and Canada, an attempt is made to discuss the effects of the experience of co-management of the so-called Autonomous

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Medication Administration (GAM - Gestao Autonoma da Medicacao) participatory research project on these individuals. By means of a detailed description of the background of the Committee and interviews and analysis of the voice transcriptions of its members, the problems raised by the relation of dialogue between scientific knowledge and users' knowledge are examined in a methodological approach of participatory research. As a result of the research, it was established that the experience of the Citizens Committee in co-management of health research can be propitious to the increase in the degree of autonomy, greater empowerment and the exercise of leadership and citizenship, with the consequent emergence of subjects with rights.

Paul, C. et Holt, J. (2017). "Involving the public in mental health and learning disability research: Can we, should we, do we?" J Psychiatr Ment Health Nurs **24**(8): 570-579.

WHAT IS KNOWN ON THE SUBJECT?: UK health policy is clear that researchers should involve the public throughout the research process. The public, including patients, carers and/or local citizens can bring a different and valuable perspective to the research process and improve the quality of research undertaken. Conducting health research is demanding with tight deadlines and scarce resources. This can make involving the public in research very challenging. WHAT THIS PAPER ADDS TO EXISTING KNOWLEDGE?: This is the first time the attitudes of researchers working in mental health and learning disability services towards PPI have been investigated. The principles of service user involvement in mental health and learning disability services may support PPI in research as a tool of collaboration and empowerment. This article extends our understanding of the cultural and attitudinal barriers to implementing PPI guidelines in mental health and learning disability services. WHAT ARE THE IMPLICATIONS FOR PRACTICE?: Researchers in mental health and learning disability services need to champion, share and publish effective involvement work. Structural barriers to PPI work should be addressed locally and successful strategies shared nationally and internationally. Where PPI guidelines are being developed, attention needs to be paid to cultural factors in the research community to win "hearts and minds" and support the effective integration of PPI across the whole research process. ABSTRACT: Introduction Patient and public involvement (PPI) is integral to UK health research guidance; however, implementation is inconsistent. There is little research into the attitudes of NHS health researchers towards PPI. Aim This study explored the attitude of researchers working in mental health and learning disability services in the UK towards PPI in health research. Method Using a qualitative methodology, semi-structured interviews were conducted with a purposive sample of eight researchers. A framework approach was used in the analysis to generate themes and core concepts. Results Participants valued the perspective PPI could bring to research, but frustration with tokenistic approaches to involvement work was also evident. Some cultural and attitudinal barriers to integrating PPI across the whole research process were identified. Discussion Despite clear guidelines and established service user involvement, challenges still exist in the integration of PPI in mental health and learning disability research in the UK. Implications for practice Guidelines on PPI may not be enough to prompt changes in research practice. Leaders and researchers need to support attitudinal and cultural changes where required, to ensure the full potential of PPI in mental health and learning disability services research is realized. Relevance statement Findings suggest that despite clear guidelines and a history of service user involvement, there are still challenges to the integration of PPI in mental health and learning disability research in the UK. For countries where PPI guidelines are being developed, attention needs to be paid to cultural factors in the

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research community to win "hearts and minds" and support the effective integration of PPI across the whole research process.

Pelletier, J. F., et al. (2014). "Pour nous, être citoyens à part entière, ça veut dire…." Santé mentale au Québec **39**(1): 311-324.
https://www.erudit.org/fr/revues/smq/2014-v39-n1-smq01474/1025919ar/

L'un des quatre principaux chapitres du document de consultation proposé par le ministère de la Santé et des Services sociaux du Québec, en préparation du Forum national sur le Plan d'action en santé mentale 2014-2020, est consacré au plein exercice de la citoyenneté. Ce témoignage est le fruit d'un dialogue tenu entre la direction générale d'un institut universitaire en santé mentale québécois et d'un groupe de personnes utilisatrices de services qui prennent part au Projet citoyen au Centre de recherche de ce même institut. Les résultats préliminaires de la validation d'une nouvelle mesure de la citoyenneté ont été utilisés pour structurer et faire progresser ce dialogue. Cette étude de cas illustre une façon de trianguler des données issues d'une recherche participative et au sein de laquelle des personnes utilisatrices de services de santé mentale ont été des partenaires de recherche à part entière. Ces pairs assistants de recherche ont notamment assumé la collecte des données auprès de 178 autres personnes utilisatrices de services de santé mentale qui ont répondu à l'échelle de la citoyenneté. Ils ont aussi animé des groupes de discussion autour des résultats préliminaires, notamment pour donner des étiquettes aux domaines émergeant des premières analyses statistiques. Ils ont ensuite dialogué avec la directrice générale venue tremper dans le Projet citoyen, et ce témoignage reflète la teneur de ce dialogue.

Petersen, K. S., Pedersen, J. F., Egilstroed, B., et al. (2020). "User involvement in developing community-based public health services: a scoping review of methods." European Journal of Public Health **30**(Supplement_5).
https://doi.org/10.1093/eurpub/ckaa166.439

User involvement in developing community-based public health services has been on the agenda for decades. User involvement refers to the variety of ways in which service users or public citizens participate in the development of health services: from proving information on their needs to actively being involved in decisions about future services. Former studies found that user involvement is meaningful to the people involved and could have a favorable impact on the quality of services. Thus, it is timely to systematically identify and provide a comprehensive overview of user involvement methods used in public health studies. The aim of this scoping review is to provide an overview of the current body of empirical research where user involvement methods have been used to develop community public health services and identify its possible impact on the individual as well as services.A systematic scoping review of user involvement methods aiming to develop public health services followed Arksey and O'Malley, 2005 framework. Six databases: CINAHL, Cochrane Library, Embase, PsycINFO. PubMed, Scopus and ProQuest, were searched from October till November, 2019. Search terms were: user involvement, methods and health care with corresponding synonym. All hits were double screened.6.044 studies were identified of which 38 studies lived up to the criteria. Preliminary findings from coding and synthesizing studies have identified a variety of user involvement19 of the studies used complex, multi-facetted packages of methods aiming to identify needs, prioritize and formulate recommendations for future services. 19 studies used different kinds of group meetings and some used certain techniques to facilitate the process.

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Many reported the impact, and 13 evaluated the methods. The impact of using the methods varied from impact on individual, group, or service/political level. Final results will be presented at the conference.Studies on user involvement methods in developing community public health services and its impact are sparse.User involvement is privotal in developing sustainable public health community services.

Polstra, L. (2001). "Empowerment of clients with severe mental illness as a challenge." Revue internationale de psychosociologie **VII**(16): 159-176.
https://www.cairn.info/revue-internationale-de-psychosociologie-2001-16-page-159.htm

RésuméLes clients atteints de maladie mentale sévère, surtout les clients qui sont aussi toxicomanes, sont reconnus comme un des groupes les plus difficiles à aider. Dans cet article deux projets de recherche-action seront décrits. Le but des deux projets était de fournir des soins sur mesure et d'améliorer la coordination entre les membres du personnel soignant concerné. Le chercheur a travaillé en étroite collaboration avec les thérapeutes dans un processus circulaire d'action, réflexion et changement. La méthode « développement » de gestion des cas s'est avérée réussie et adéquate pour résoudre le problème de l'action (l'adéquation est l'un des deux critères pour la qualité d'une recherche-action). Les thérapeutes sont devenus des personnages clés dans la réforme du système de soins pour les malades mentaux dans la ville de Groningen. Les projets de recherche-action ont contribué à leur émancipation, deuxième critère de qualité de la recherche-action. Les clients profitent individuellement des résultats des réformes. Les projets n'ont pas réussi dans le processus d'émancipation des clients. L'incapacité à fonctionner au sein d'un groupe entrave ce processus.

Pomey, M.-P., Flora, L., Karazivan, P., et al. (2015). "Le "Montreal model" : enjeux du partenariat relationnel entre patients et professionnels de la santé." Santé Publique **27**: 41-50, fig.

[BDSP. Notice produite par EHESP R0x8Am9l. Diffusion soumise à autorisation]. Depuis 2010, un nouveau modèle relationnel, basé sur le partenariat entre les patients et les professionnels de la santé, a été développé à la Faculté de médecine de l'Université de Montréal. Ce modèle de partenariat patient s'appuie sur la reconnaissance des savoirs expérientiels du patient, issus de la vie avec la maladie, et complémentaires des savoirs scientifiques des professionnels de la santé. Il s'inscrit dans un continuum d'engagement des patients et peut s'appliquer dans les milieux de soins, de la formation des professionnels, de l'enseignement et de la recherche. Les fondements théoriques du partenariat patient sont exposés ici, ainsi que la manière dont ce nouveau modèle peut être mis en oeuvre aux niveaux clinique, organisationnel et systémique et quels en sont les facteurs de réussite tant du côté des patients que des professionnels de la santé.

Presotto, R. F., et al. (2013). "[Brazilian experiences in the participation of users and family members in mental health research]." Cien Saude Colet **18**(10): 2837-2845.

In this paper the authors describe and contextualize the participation of users and family members in mental health research in Brazil, addressing the recent tradition of the experiences of recovery and empowerment to define the analysis of some Brazilian experiences of evaluative research and intervention projects, which count on these social actors to act as researchers. The experiences of Self-Help Groups and the Guide to Autonomous Medication Management are described briefly, in order to analyze the limits and possibilities of

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participation of users and their family members in research, which is still incipient and sporadic in the Brazilian reality. The authors also recommend the creation of an agenda in public health policy that encourages this participation.

Proctor, E. K., et al. (2009). "Implementation Research in Mental Health Services: an Emerging Science with Conceptual, Methodological, and Training challenges." Adm Policy Ment Health **36**(1): 10.1007/s10488-10008-10197-10484.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3808121/

> One of the most critical issues in mental health services research is the gap between what is known about effective treatment and what is provided to consumers in routine care. Concerted efforts are required to advance implementation science and produce skilled implementation researchers. This paper seeks to advance implementation science in mental health services by over viewing the emergence of implementation as an issue for research, by addressing key issues of language and conceptualization, by presenting a heuristic skeleton model for the study of implementation processes, and by identifying the implications for research and training in this emerging field.

Pullmann, M. D. (2009). "Participatory research in systems of care for children's mental health." Am J Community Psychol **44**(1-2): 43-53.

Puyalto, C., et al. (2016). "Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research." J Appl Res Intellect Disabil **29**(2): 146-159.

> BACKGROUND: Despite an increase in inclusive studies in recent years, research on the views of the people with and without disabilities who have participated in these studies is scarce. The aim of this study was to explore the perceptions and views of advisors with intellectual disabilities and non-disabled researchers who collaborated together on a joint project to study transition to adulthood. MATERIALS AND METHODS: Two questionnaires were devised, one for advisors and one for researchers; two focus groups were held with people with intellectual disabilities, three focus groups with researchers, and one focus group with all participants together. Thematic analysis was used for the data analysis. RESULTS: The advisors valued this experience as an opportunity to learn new skills, freely express themselves on matters that affect them, and engage in a socially valued activity. The researchers considered that the participation of people with intellectual disabilities contributed to improving the quality of the research. CONCLUSIONS: The study provides a better understanding of inclusive research processes by taking into account participants' views.

Restall, G., et al. (2011). "Pathways to translating experiential knowledge into mental health policy." Psychiatr Rehabil J **35**(1): 29-36.

> OBJECTIVE: This research explored the pathways through which the experiential knowledge of people who need and use mental health and social housing services (citizen-users) gains access to policymaking. METHODS: Qualitative instrumental case study methodology focused the study on the policy field of mental health and social housing in Manitoba, Canada. Data collection included interviews with 21 key informants from four policy actor groups: citizen-users, service providers, advocacy organization representatives, and government officials. Relevant policy-

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related documents were also reviewed. Data were analyzed using inductive qualitative methods. RESULTS: Key informants described diverse pathways through which the experiential knowledge of citizen-users has been communicated to policy decision makers. Pathways have involved direct discourse between citizen-users and decision makers. Alternatively, indirect pathways were ones in which experiential knowledge was translated by other policy actors. Informants identified factors that could influence the integrity of the indirect pathways: the length and complexity of the pathways, the motivations and interests of the translators, and strategies to enhance the pathways. The pathways could be strengthened by developing the culture, leadership, knowledge, skills and attitudes supportive of engaging citizen-users and by accurately translating their experiential knowledge. CONCLUSIONS AND IMPLICATIONS FOR PRACTICE: If citizen-users are to be included in policymaking in a recovery-oriented mental health system, action must be taken to enhance the pathways through which their experiential knowledge reaches policymaking processes. Service providers, advocacy organization representatives and government officials can all take action to promote social policymaking that is informed by citizen-users' ideas and experiences.

Reupert, A., Ward, B., McCormick, F., et al. (2018). "Developing a model of family focused practice with consumers, families, practitioners and managers: a community based participatory research approach." BMC Health Serv Res **18**(1): 66.

BACKGROUND: While governments are urging adult mental health services to support consumers in the context of their family, there is little information about what family focused practice is, nor how it might be enacted. METHODS: Informed by the principles of Community Based Participatory Research, workshops were held in three rural Australian communities in 2015 to discuss the meaning of family focused practice and how such practices might be promoted. RESULTS: Participants described the need to raise community awareness about mental illness and provide practical support to the family. Participants emphasized the importance of practitioners genuinely communicating with consumers and their families about mental illness and the need for collaborative care and treatment planning. They also highlighted the challenges of living in rural places and posed some solutions. CONCLUSION: On the basis of the results and previous literature, we developed a model of family focused practice that outlined various stakeholders and their enactments. The model has the potential to inform policy, professional development and practice guidelines.

Richter, M., et al. (2011). "[Information and participation of patients in psychosomatic rehabilitation. Occurrence and relations to patient satisfaction treatment outcome]." Psychiatr Prax **38**(5): 237-243.

OBJECTIVE: Main goal was to assess the wish for participation of patients in psychosomatic rehabilitation and their perception of medical information and own treatment involvement. Further, the influence of these constructs on patient satisfaction was investigated. METHODS: 276 patients were included in a cross-sectional survey at the end of their inpatient stay. RESULTS: Patients showed a strong need for participation in this sample. Socio-demographic and disease-related parameters had no or only weak associations to the shared decision making variables. Strong correlations to patient satisfaction were found for doctor facilitation of patient involvement (r = 0.57) and transfer of treatment relevant information (r = 0.52). CONCLUSIONS: The doctor's behaviour concerning information transfer and involvement of patients in their treatment proved to be an important factor for patient satisfaction. This underlines the importance of active and need-oriented information in the sense of "empowerment".

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Rogers, E. S. et Palmer-Erbs, V. (1994). "Participatory Action Research: Implications for research and evaluation in psychiatric rehabilitation." Psychosocial Rehabilitation Journal **18**(2): 3.

Rose, D. (2018). "Participatory research: real or imagined." Soc Psychiatry Psychiatr Epidemiol **53**(8): 765-771.

> BACKGROUND: Participatory research has as a central tenet that power relations between researcher and researched be reduced. In the last 20 years, a substantial literature has demonstrated the difficulties inherent in this as well as the troublesome nature of certain central concepts. AIMS: (1) To describe and illustrate a new form of participatory research where the researchers share at least something with the participants in the research. That is, all are users of mental health services. (2) To reflect on the novel form of participatory research in terms of whether it shares, mitigates or avoids some of the difficulties of more traditional forms and to pose the question: what is a mental health community? RESULTS: The model described is new in that the researchers have a different status than in conventional participatory research. But it is illuminated by and itself illuminates issues of power relations in research and difficulties in reducing that; gatekeepers and the exclusion of crucial groups of service users; the confusion of demographic representativeness with the silencing of marginalized perspectives; coming out of the academic space and the shifting issue of what counts as 'communities' in mental health. CONCLUSION: The examples given are moderate in scale and relevant to social psychiatry. Yet they may change methods and the definition of participatory research and at the same time be vitiated by but also illuminate dilemmas already identified in the literature albeit in different formations.

Ruelland, I. (2015). "Les dispositifs de délibération en santé mentale et la démocratisation des échanges entre les pairs : le cas de l'assemblée des usagers d'un centre d'attention psychosociale au Brésil." Santé mentale au Québec **40**(1): 153-170.
http://id.erudit.org/iderudit/1032388ar

> Le réseau public de services de santé mentale de la ville de Campinas dans l'État de São Paulo au Brésil est constitué de divers dispositifs de délibération impliquant des personnes utilisatrices. L'assemblée des usagers dans les centres d'attention psychosociale (CAPS) constitue un exemple clé de ce genre d'innovation participative fondée sur des principes de démocratisation et de justice sociale. Est-ce que l'assemblée des usagers comme dispositif délibératif institué agit sur les inégalités sociales de pouvoir et le rétablissement des personnes ? Il s'agit ici de rendre compte de certains résultats d'une recherche qui a pour objectif de saisir si de tels dispositifs agissent sur la démocratisation des rapports sociaux du point de vue des personnes utilisatrices impliquées, et comment. À partir d'une ethnographie organisationnelle de près d'un an dans un CAPS du réseau public de santé mentale de Campinas, il a été constaté comment les échanges créés au sein et en dehors de l'assemblée des usagers participent à l'émergence d'une forme de pair-aidance spontanée et informelle. Ce constat permet de réfléchir sur le rapport entre cette pair-aidance implicite et la circulation des personnes dans une pluralité d'espaces collectifs ouverts dans lesquels celles-ci peuvent partager des affects et critiquer librement au sujet des services reçus.

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Ryan, G. K., Semrau, M., Nkurunungi, E., et al. (2019). "Service user involvement in global mental health: what have we learned from recent research in low and middle-income countries?" Curr Opin Psychiatry **32**(4): 355-360.

> PURPOSE OF REVIEW: The Lancet Commission on global mental health and sustainable development claims the field of global mental health is undergoing a 'transformational shift' toward an ethic of 'nothing about us without us'. Yet a systematic review published in 2016 identified few examples of meaningful participation by service users in mental health systems strengthening in low and middle-income countries (LMICs). To investigate whether this is still the case, we conducted a rapid review of primary research published between June 2017 and December 2018. RECENT FINDINGS: We identified 10 studies reporting on user involvement in LMICs, including three in mental health policy and planning, three in mental health services or capacity-building and three in treatment decision-making. An additional study was identified as having involved users in data collection, although this was unclear from the original text. Included studies were mostly qualitative and conducted as part of a situation analysis, pilot study, or other formative research. Few reported the results of efforts to improve involvement, suggesting this shift remains at an early stage. SUMMARY: Although the number of studies published on user involvement is rapidly increasing, the potentially 'transformational' effects of this shift in global mental health are not yet being felt by most users in LMICs.

Sabbe, B., et al. (2010). "Research projects in the collaborative antwerp psychiatric research institute." Psychiatr Danub **22 Suppl 1**: S95-105.

> INTRODUCTION: In the following article CAPRI presents its current research projects. SUBJECTS AND METHOD: The team leaders were asked to present and summarize the project they had been working on. The fields in which research was conducted are: Child and Adolescent Psychiatry, Cognitive and Psychomotor Dysfunctions in Schizophrenia, fMRI in Schizophrenia, Cognitive and Psychomotor Dysfunctions in Major Depressive Disorder, Chronic Fatigue Syndrome, Addiction Medicine and Forensic Psychiatry. RESULTS: An overview of recent and ongoing research projects is provided and the main results are summarized.

Salmon, A., et al. (2010). "'Now we call it research': participatory health research involving marginalized women who use drugs." NursInq **17**(4): 336-345.

> In this paper, we discuss and analyse the strategies employed and challenges encountered when conducting a recent feminist participatory action research study with highly marginalized women who were illicit drug users in an inner city area of Vancouver, Canada. Through an analysis of the political economy of participatory praxis within current neoliberal contexts, we focus on three main areas: (i) reconceptualizing the pragmatics of participation; (ii) the microeconomic implications of participatory research, including ethical issues in payment for research participation; and (iii) the value and limits of using research as a tool for activism and empowerment. We conclude with a brief discussion of what we see to be some of the most salient social justice implications arising from feminist and participatory approaches to health research within neoliberal political spaces.

Salvi, G., et al. (2005). "[Systematic review of the role of service users as researchers in mental health studies]." Epidemiol Psichiatr Soc **14**(4): 217-226.

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AIMS: Service user involvement in mental health service development and research is becoming more common in countries like the UK, USA and Canada. This systematic review of the international scientific literature has been carried out to assess the stage of development of mental health service users involvement in research. METHOD: Systematic review of any research project actively involving service users in any part of the research process. RESULTS: Thirty-five studies met the inclusion and exclusion criteria and were included in the systematic review. Nine studies used quantitative techniques, 24 used qualitative techniques and two studies used both quantitative and qualitative techniques. While three studies were user-led, in three other studies the users were simply consulted but did not have any active role in the research. The remaining 29 studies were based on a collaboration between service users and professional researchers. CONCLUSIONS: The involvement of mental health service users in the research process is feasible both in quantitative and qualitative research studies. The involvement of service users in research has a number of benefits; such research requires more accurate planning and more time than the traditional research.

Sanchez-Moscona, C. et Eiroa-Orosa, F. J. (2021). "Training mental health peer support training facilitators: a qualitative, participatory evaluation." Int J Ment Health Nurs **30**(1): 261-273.

The facilitator's training for peer support workers in mental health course was a recovery-based initiative addressed to professionalize peer support in Catalonia, Spain. Our aim was to elicit participants' motivations, significant learnings, and opinions regarding the training programme. A qualitative approach was used through content and thematic analyses of the course contents and participation narratives. The motivations to attend the course were helping others, learning, and supporting the implementation of the peer support profession. Participants learnt concepts on pedagogy, peer support, and recovery. The key resulting themes were organization and moderation; peer support's role, skills, functions, and values; language; health system knowledge; and types of support. The course programme seems appropriate in preparing people who have lived experience of mental health problems as facilitators of future peer support training courses. The present analysis identifies the participants' vision regarding their learning needs. It aims to serve as a guide for similar train-the-trainers courses.

Sangill, C., Buus, N., Hybholt, L., et al. (2019). "Service user's actual involvement in mental health research practices: A scoping review." Int J Ment Health Nurs **28**(4): 798-815.

Service user involvement in mental health research is on the international political agenda, for example mirrored by an emphasis on user involvement in funding of research. The idea is that service users contribute with their lived experiences of mental distress to the research process and thereby heighten the quality and relevance of the research. The purpose of this scoping review was to identify and evaluate empirical research of how mental health service users actually partake in collaborative research processes and to summarize this research in dialogue with mental health user-researchers. The review included 32 studies. Main findings indicated that actual involvement of service user-researchers in research processes encompassed a complex set of precarious negotiation practices, where academics and service user-researchers were positioned and positioned themselves in alternative ways. The review accounts for how mental health service users were involved in collaborative research processes. The extracted themes concerned: (i) Expectations of research processes, (ii) Contribution to research processes, and (iii) Training and learning from research processes. The study reveals that collaborative research in mental health requires changes to traditional research practices to

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create and support genuine collaborative partnerships and thereby avoid tokenism and power inequalities.

Schafer, I., et al. (2011). "Attitudes of patients with schizophrenia and depression to psychiatric research: a study in seven European countries." Soc Psychiatry Psychiatr Epidemiol **46**(2): 159-165.

BACKGROUND: Relatively few studies have examined how patients with schizophrenia and depression view psychiatric research and what influences their readiness to participate. METHODS: A total of 763 patients (48% schizophrenia, 52% depression) from 7 European countries were examined using a specifically designed self-report questionnaire ["Hamburg Attitudes to Psychiatric Research Questionnaire" (HAPRQ)]. RESULTS: Most patients (98%) approved of psychiatric research, in general, at least "a little". There was a tendency to approve psychosocial rather than biological research topics (e.g. research on the role of the family by 91% of patients compared to 79% in genetics). Reasons to participate were mainly altruistic. Only a minority (28%) considered monetary incentives important. Patients wanted extensive background information and a feedback of the results; both were significantly more expressed by schizophrenia as compared to depressive patients, although these findings need to be interpreted with care because of age and gender differences between the diagnostic groups. CONCLUSION: While patients expressed discerning views of psychiatric research, only few differences were apparent between the two diagnostic groups. Patients' research priorities are not the same as those of many professionals and funding bodies. Their demonstrated critical appraisal should inform future research ensuring an increased patient role in the research process.

Schneider, B. (2012). "Participatory action research, mental health service user research, and the hearing (our) voices projects." International Journal of Qualitative Methods **11**(2): 152-165.

Schneider, B., et al. (2004). "Communication between people with schizophrenia and their medical professionals: A participatory research project." Qual Health Res **14**(4): 562-577.

Scholz, B., Roper, C., Juntanamalaga, P., et al. (2019). "Understanding the Role of Allies in Systemic Consumer Empowerment: A Literature Review." Issues Ment Health Nurs **40**(4): 354-361.

Contemporary mental health policies call for the inclusion of consumers in the development, implementation and evaluation of mental health services. Barriers to systemic consumer engagement have been related to unequal distributions of power. One of the goals of the consumer movement is to address imbalances of power, resources and knowledge. Empowerment through consumer leadership in the mental health sector has been identified as a fundamental goal of the consumer movement and has been considered the philosophical basis for alternative models of mental health care. However, currently such systemic empowerment is poorly understood, assuming diverse and at times contradictory definitions within mental health literature. The role of allies as facilitators of systemic empowerment opportunities has been recognised and valued within numerous social movements. Currently, there is a lack of research in regards to the potential role of allies in the consumer movement and more specifically in systemic consumer empowerment. Future research should seek to more clearly define systemic consumer empowerment. Additionally, future research collaborations between consumer and ally perspectives should specifically investigate the role of allies in systemic consumer empowerment, to highlight potential opportunities and limitations.

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Schwartz, R., et al. (2013). "Mental health consumers and providers dialogue in an institutional setting: a participatory approach to promoting recovery-oriented care." Psychiatr Rehabil J **36**(2): 113-115.

OBJECTIVE: This brief report presents the preliminary findings of a participatory project, to answer a question raised by stakeholders in mental health services: How can providers and patients create a process for knowledge exchange to support recovery-oriented care? METHOD: Participatory action research (PAR) and narrative phenomenological methodology guided the selection of methods, which consisted of an iterative process between telling stories and dialoguing about personal values related to recovery. The sample consisted of three occupational therapists, a psychiatrist, an academic-clinician, and five consumers of mental health services who were involved in each stage of the research, including design, interpretation, dissemination, and implementation. RESULTS: Significant interpersonal and intrapersonal tensions were named, and conditions for a more sustainable process of knowledge exchange were explored. CONCLUSIONS AND IMPLICATIONS FOR PRACTICE: The project revealed both the challenges with situating research within an institution (hierarchy of knowledge, power, and vulnerability) and face-to-face dialogue, as well as positive changes in professional attitudes and consumer empowerment, as providers and patients came to understand what was at stake for each other. The project underscored the need for provider-consumer dialogue as a process to explore tensions and values in promoting recovery-oriented care.

Shalaby, R. A. H. et Agyapong, V. I. O. (2020). "Peer Support in Mental Health: Literature Review." JMIR Ment Health **7**(6): e15572.

BACKGROUND: A growing gap has emerged between people with mental illness and health care professionals, which in recent years has been successfully closed through the adoption of peer support services (PSSs). Peer support in mental health has been variously defined in the literature and is simply known as the help and support that people with lived experience of mental illness or a learning disability can give to one another. Although PSSs date back to several centuries, it is only in the last few decades that these services have formally evolved, grown, and become an integral part of the health care system. Debates around peer support in mental health have been raised frequently in the literature. Although many authors have emphasized the utmost importance of incorporating peer support into the health care system to instill hope; to improve engagement, quality of life, self-confidence, and integrity; and to reduce the burden on the health care system, other studies suggest that there are neutral effects from integrating PSSs into health care systems, with a probable waste of resources. OBJECTIVE: In this general review, we aimed to examine the literature, exploring the evolution, growth, types, function, generating tools, evaluation, challenges, and the effect of PSSs in the field of mental health and addiction. In addition, we aimed to describe PSSs in different, nonexhaustive contexts, as shown in the literature, that aims to draw attention to the proposed values of PSSs in such fields. METHODS: The review was conducted through a general search of the literature on MEDLINE, Google Scholar, EMBASE, Scopus, Chemical Abstracts, and PsycINFO. Search terms included peer support, peer support in mental health, social support, peer, family support, and integrated care. RESULTS: There is abundant literature defining and describing PSSs in different contexts as well as tracking their origins. Two main transformational concepts have been described, namely, intentional peer support and transformation from patients to peer support providers. The effects of PSSs are extensive and integrated into different fields, such as forensic PSSs, addiction,

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and mental health, and in different age groups and mental health condition severity. Satisfaction of and challenges to PSS integration have been clearly dependent on a number of factors and consequently impact the future prospect of this workforce. CONCLUSIONS: There is an internationally growing trend to adopt PSSs within addiction and mental health services, and despite the ongoing challenges, large sections of the current literature support the inclusion of peer support workers in the mental health care workforce. The feasibility and maintenance of a robust PSS in health care would only be possible through collaborative efforts and ongoing support and engagement from all health care practitioners, managers, and other stakeholders.

Shalowitz, M. U., et al. (2009). "Community-based participatory research: a review of the literature with strategies for community engagement." Journal of Developmental & Behavioral Pediatrics **30**(4): 350-361.

Shattell, M. M., et al. (2008). "Mental health service needs of a Latino population: a community-based participatory research project." Issues Ment Health Nurs **29**(4): 351-370.

> Community-based participatory research bridges the gap between academic researchers and the real-life issues of communities and offers promise for addressing racial and ethnic disparities in mental health care. The purpose of this community-based participatory research was to identify factors that affect access, use, and perception of mental health services by a Latino population at individual, organizational, and community levels. Individual level factors included health beliefs about mental illness and care, suspicions of providers, financial concerns, and culturally determined gender roles. Organizational factors included problems with access to care related to cost, lack of bilingual providers, and culturally competent care; and community level factors included distance between resources and the need for services to be provided in community sites. Immigration status and acculturation were identified as factors at all levels.

Short, K. H., et al. (2012). "Tying together research and practice: using ROPE for successful partnerships in school mental health." Adm Policy Ment Health **39**(4): 238-247.

> There is solid evidence for strategies and programs that, if implemented with fidelity in schools, will enhance the mental health of children and youth. These practices are, however, inconsistently applied and rarely evaluated programmatically in every day practice. In recent years, implementation variables that influence uptake have received attention. An emerging area of interest is the role that research partnerships might play in narrowing the gap between science and practice. Drawing on the literature and practice examples, collaborators from the United States and Canada explore the role of partnerships in bringing the worlds of research and practice closer into alignment.

Small, N., et al. (2017). "Understanding experiences of and preferences for service user and carer involvement in physical health care discussions within mental health care planning." BMC Psychiatry **17**(1): 138.

> BACKGROUND: People with severe mental illness suffer more physical comorbidity than the general population, which can require a tailored approach to physical health care discussions within mental health care planning. Although evidence pertaining to service user and carer involvement in mental health care planning is accumulating, current understanding of how physical health is prioritised within this framework is limited. Understanding stakeholder

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experiences of physical health discussions within mental health care planning, and the key domains that underpin this phenomena is essential to improve quality of care. Our study aimed to explore service user, carer and professional experiences of and preferences for service user and carer involvement in physical health discussions within mental health care planning, and develop a conceptual framework of effective user-led involvement in this aspect of service provision. METHODS: Six focus groups and four telephone interviews were carried out with twelve service users, nine carers, three service users with a dual service user and carer role, and ten mental health professionals recruited from one mental health Trust in the United Kingdom. Data was analysed utilising a thematic approach, analysed separately for each stakeholder group, and combined to aid comparisons. RESULTS: No service users or carers recalled being explicitly involved in physical health discussions within mental health care planning. Six prerequisites for effective service user and carer involvement in physical care planning were identified. Three themes confirmed general mental health care planning requirements: tailoring a collaborative working relationship, maintaining a trusting relationship with a professional, and having access to and being able to edit a living document. Three themes were novel to feeling involved in physical health care planning discussions: valuing physical health equally with mental health; experiencing coordination of care between physical-mental health professionals, and having a physical health discussion that is personalised. CONCLUSIONS: High quality physical health care discussions within the care planning process demands action at multiple levels. A conceptual framework is presented which provides an evidence-based foundation for service level improvement. Further work is necessary to develop a new patient reported outcome measure to enable meaningful quantification of health care quality and patient experience.

Solberg, L. I., et al. (2010). "Partnership research: a practical trial design for evaluation of a natural experiment to improve depression care." Med Care **48**(7): 576-582.

BACKGROUND: Translational research is increasingly important as academic health centers transform themselves to meet new requirements of National Institutes of Health funding. Most attention has focused on T1 translation studies (bench to bedside) with considerable uncertainty about how to enhance T2 (effectiveness trials) and especially T3 (implementation studies). OBJECTIVE: To describe an innovative example of a T3 study, conducted as partnership research with the leaders of a major natural experiment in Minnesota to improve the primary care of depression. METHODS: All health plans in the state have agreed on a new payment model to support clinics that implement the well-evidenced collaborative care model for depression in the Depression Improvement Across Minnesota: Offering a New Direction initiative. The Depression Improvement Across Minnesota: Offering a New Direction study was developed in an ongoing partnership with the Initiative leaders from 7 health plans, 85 clinics, and a regional quality improvement collaborative to evaluate the implementation and its impacts on patients and other stakeholders. We agreed on a staggered implementation, multiple baseline research design, using the concepts of practical clinical trials and engaged scholarship and have collaborated on all aspects of conducting the study, including joint identification of patient and clinic survey recipients. RESULTS: Complex study methods have worked well through 20 months because of the commitment of all stakeholders to both the Initiative and the Study. Over 1500 subjects have been recruited from health plan information delivered weekly, and 99.7% of 316 physicians and administrators from all participating clinical organizations have completed the Study surveys. CONCLUSIONS: Partnership research can greatly facilitate translational research studies.

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Sox, C. M., et al. (2010). "Patient-centered design of an information management module for a personally controlled health record." <u>J Med Internet Res</u> **12**(3): e36.

> BACKGROUND: The development of health information technologies should be informed by iterative experiments in which qualitative and quantitative methodologies provide a deeper understanding of the abilities, needs, and goals of the target audience for a personal health application. OBJECTIVE: Our objective was to create an interface for parents of children with attention-deficit hyperactivity/disorder (ADHD) to enter disease-specific information to facilitate data entry with minimal task burden. METHODS: We developed an ADHD-specific personal health application to support data entry into a personally controlled health record (PCHR) using a three-step, iterative process: (1) a needs analysis by conducting focus groups with parents of children with ADHD and an heuristic evaluation of a prerelease version of a PCHR, (2) usability testing of an initial prototype personal health application following a "think aloud" protocol, (3) performance testing of a revised prototype, and (4) finalizing the design and functionality of the ADHD personal health application. Study populations for the three studies (focus groups and two usability testing studies) were recruited from organizations in the greater Boston area. Study eligibility included being an English- or Spanish-speaking parent who was the primary caretaker of a school-age child with ADHD. We determined subjects' health literacy using the Test of Functional Health Literacy in Adults (TOFHLA). We assessed subjects' task burden using the National Aeronautics and Space Administration (NASA) Task Load Index. To assess the impact of factors associated with the time spent entering data, we calculated Pearson correlation coefficients (r) between time on task and both task burden and subject characteristics. We conducted t tests to determine if time on task was associated with successful task completion. RESULTS: The focus groups included three cohorts: 4 Spanish-speaking parents with diverse health literacy, 4 English-speaking parents with lower health literacy, and 7 English-speaking parents with higher health literacy. Both the initial usability testing cohort (n = 10) and the performance-testing cohort (n = 7) included parents of diverse health literacy and ethnicity. In performance testing, the prototype PCHRs captured patient-specific data with a mean time on task of 11.9 minutes (SD 6.5). Task burden experienced during data entry was not associated with successful task completion (P = .92). Subjects' past computer experience was highly correlated with time on task (r = .86, P = .01), but not with task burden (r = .18, P = .69). The ADHD personal health application was finalized in response to these results by (1) simplifying the visual environment, (2) including items to support users limited by health literacy or technology experience, and (3) populating the application's welcome screen with pictures of culturally diverse families to establish a personal family-oriented look and feel. CONCLUSIONS: Our patient-centered design process produced a usable ADHD-specific personal health application that minimizes the burden of data entry.

Sperlich, S. (2008). "[Correlation between social status, empowerment processes and the development of psychological health]." <u>Gesundheitswesen</u> **70**(12): 779-790.

> The aim of this paper is to deepen our knowledge about empirical evidence of empowerment on the basis of follow-up data from mother-child rehabilitation centres. The study focusses on three questions: i) to what extent can psychological health in different socioeconomic groups be improved by the intervention?, ii) Is there an impact of social position on the success of empowerment and iii) Is there any relevance of empowerment for sustainable improvement of psychological health? The study is based on data from 6 095 patients of 39 mother-child rehabilitation centres in Germany, collected up to one year after intervention. Empowerment

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was assessed by two self-defined scales, measuring positive changes i) in living circumstances, such as partnership or household ('Verhaltnis-Empowerment') and ii) in health-related behaviours and competencies, such as better coping with problems and higher health awareness ('Verhaltens-Empowerment'). Health status was assessed by psychological symptoms and measured by SCL-K-9, a short form of the SCL-90-R. The socioeconomic position was determined by cluster analysis, the influence of social position and empowerment for psychological health was computed by analysis of regression. Before intervention mothers from the lower class showed higher degrees of psychological symptoms. After intervention they reached higher short-term effects, but six months later psychological symptoms increased again. In particular improvement of health-related behaviours and competencies was associated with better psychological health. The highest impact on health was found among mothers from the middle and lower class. These mothers, however, showed less success in optimising health-related behaviours and competencies. Twelve months after treatment the health-related impact of empowerment decreased. The theoretical evidence of empowerment could be empirically confirmed. However, decreasing health effects of empowerment after twelve months show that supporting help after clinical intervention is necessary to maintain the positive impact of empowerment. Only small differences in empowerment between lower and middle class lead to the conclusion that terms of social class are less appropriate for the clinical sample of mothers investigated in this study.

Stacciarini, J. M. (2009). "A review of community-based participatory research: a promising approach to address depression among Latinos?" Issues Ment Health Nurs **30**(12): 751-757.

US Latinos are almost twice as likely as Whites to experience depression in a given year, and to date, there is a gap in understanding how to effectively address depression in this population. This study reviews community-based participatory research (CBPR) publications involving Latinos and depression. The specific aims were to: (1) describe studies using CBPR for addressing depression among Latinos, and (2) identify challenges and lessons learned when using CBPR for addressing depression among Latinos. Electronic databases and the grey literature were reviewed for publications that included CBPR, Latinos, and depression, published between 1990 and 2008. Although few studies were identified, this review provides a baseline synopsis that can serve mental health researchers when developing studies to test/validate CBPR with this underserved population.

Stacciarini, J. M., et al. (2011). "Review: Community-based participatory research approach to address mental health in minority populations." Community Ment Health J **47**(5): 489-497.

In this review, a synthesis of studies employing community-based participatory research (CBPR) to address mental health problems of minorities, strengths and challenges of the CBPR approach with minority populations are highlighted. Despite the fact that minority community members voiced a need for innovative approaches to address culturally unique issues, findings revealed that most researchers continued to use the traditional methods in which they were trained. Moreover, researchers continued to view mental health treatment from a health service perspective.

Staniszewska, S., Mockford, C., Chadburn, G., et al. (2019). "Experiences of in-patient mental health services: systematic review." Br J Psychiatry **214**(6): 329-338.

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BACKGROUND: In-patients in crisis report poor experiences of mental healthcare not conducive to recovery. Concerns include coercion by staff, fear of assault from other patients, lack of therapeutic opportunities and limited support. There is little high-quality evidence on what is important to patients to inform recovery-focused care.AimsTo conduct a systematic review of published literature, identifying key themes for improving experiences of in-patient mental healthcare. METHOD: A systematic search of online databases (MEDLINE, PsycINFO and CINAHL) for primary research published between January 2000 and January 2016. All study designs from all countries were eligible. A qualitative analysis was undertaken and study quality was appraised. A patient and public reference group contributed to the review. RESULTS: Studies (72) from 16 countries found four dimensions were consistently related to significantly influencing in-patients' experiences of crisis and recovery-focused care: the importance of high-quality relationships; averting negative experiences of coercion; a healthy, safe and enabling physical and social environment; and authentic experiences of patient-centred care. Critical elements for patients were trust, respect, safe wards, information and explanation about clinical decisions, therapeutic activities, and family inclusion in care. CONCLUSIONS: A number of experiences hinder recovery-focused care and must be addressed with the involvement of staff to provide high-quality in-patient services. Future evaluations of service quality and development of practice guidance should embed these four dimensions.Declaration of interestK.B. is editor of British Journal of Psychiatry and leads a national programme (Synergi Collaborative Centre) on patient experiences driving change in services and inequalities.

Stirman, S. W., et al. (2010). "Developing research and recruitment while fostering stakeholder engagement in a National Institutes of Mental Health-funded Interventions and Practice Research Infrastructure Programs grant for depression." Prog Community Health Partnersh **4**(4): 299-303.

BACKGROUND: In the context of a National Institutes of Mental Health-funded Interventions and Practice Research Infrastructure Programs (IP-RISP) grant for the treatment of depression, a partnership was developed between a community mental health organization and a team of researchers. OBJECTIVES: This paper describes the collaborative process, key challenges, and strategies employed to meet the goals of the first phase of the grant, which included development of a working and sustainable partnership and building capacity for recruitment and research. METHODS: This paper was developed through the use of qualitative interviews and discussion with a variety of IP-RISP partners. LESSONS LEARNED: Communication with multiple stakeholders through varied channels, feedback from stakeholders on research procedures, and employing a research liaison at the clinic have been key strategies in the first phase of the grant. CONCLUSION: The strategies we employed allowed multiple stakeholders to contribute to the larger mission of the IP-RISP and helped to establish an ongoing research program within the mental health organization.

Stratford, A. C., Halpin, M., Phillips, K., et al. (2019). "The growth of peer support: an international charter." J Ment Health **28**(6): 627-632.

Objective: While mental health peer support originated in its contemporary form in English-speaking countries, it is now spreading rapidly across the globe. This rapid growth presents two major challenges. The first pertains to "role integrity" and the second to the possible culture-bound nature of peer support; a concern which has attended the emergence of peer support in countries that have significantly different worldviews.Method: Recognizing the growth of peer support and the resulting challenges, this report results from the convening of an international

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consortium of peer leaders from six continents (all but Antarctica). Following an environmental scan of the state of peer support globally, this group moved to develop consensus on a common, core set of guiding principles and values to ensure a robust future for the development of effective, culturally responsive forms of peer support.Findings: Key principles, values and practices considered essential to peer support are presented.Conclusions and implications for practice: Assuming that sufficient political and community support are generated, there can be considerable enthusiasm for the expansion of peer support around the globe. Peer leaders are encouraged, however, to develop and deliver peer support both with integrity to its founding values in a civil rights and social justice framework and with responsiveness to local cultural worldviews.

Sullivan, G., et al. (2007). "Design of the Coordinated Anxiety Learning and Management (CALM) study: innovations in collaborative care for anxiety disorders." Gen Hosp Psychiatry **29**(5): 379-387.

BACKGROUND: Despite a marked increase in the number of persons seeking help for anxiety disorders, the care provided may not be evidence based, especially when delivered by nonspecialists. Since anxiety disorders are most often treated in primary care, quality improvement interventions, such as the Coordinated Anxiety Learning and Management (CALM) intervention, are needed in primary care. RESEARCH DESIGN: This study is a randomized controlled trial of a collaborative care effectiveness intervention for anxiety disorders. SUBJECTS: Approximately 1040 adult primary care patients with at least one of four anxiety disorders (generalized anxiety disorder, panic disorder, posttraumatic stress disorder or social anxiety disorder) will be recruited from four national sites. INTERVENTION: Anxiety clinical specialists (ACSs) deliver education and behavioral activation to intervention patients and monitor their symptoms. Intervention patients choose cognitive-behavioral therapy, antianxiety medications or both in "stepped-care" treatment, which varies according to clinical needs. Control patients receive usual care from their primary care clinician. The innovations of CALM include the following: flexibility to treat any one of the four anxiety disorders, co-occurring depression, alcohol abuse or both; use of on-site clinicians to conduct initial assessments; and computer-assisted psychotherapy delivery. EVALUATION: Anxiety symptoms, functioning, satisfaction with care and health care utilization are assessed at 6-month intervals for 18 months. CONCLUSION: CALM was designed for clinical effectiveness and easy dissemination in a variety of primary care settings.

Sunkel, C. (2012). "Empowerment and partnership in mental health." Lancet **379**(9812): 201-202.

Sylvia, L. G., Hearing, C. M., Montana, R. E., et al. (2018). "MoodNetwork: An Innovative Approach to Patient-centered Research." Med Care **56 Suppl 10 Suppl 1**(10 Suppl 1): S48-s52.

INTRODUCTION: Research has often been viewed as a passive process by which participants enroll in studies developed by researchers. It is becoming clearer that to understand the nuances of mood episodes and how to prevent them, we need to conduct large clinical trials that have the power to investigate moderators and mediators, or catalysts and mechanisms of change. MoodNetwork, the first online, patient-centered research community for individuals with mood disorders, aims to change the way that traditional research has been conducted by involving patients, their caregivers, and advocates in the process of research. The aim of this report is to share lessons learned from developing MoodNetwork. METHODS: Participants enroll by completing a demographic survey and consent form. Once enrolled, participants are

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encouraged to complete optional surveys about their mood disorders and areas of research priority. Stakeholder and advocacy partners developed the website, web-based surveys, and recruitment materials. RESULTS: MoodNetwork has enrolled 4103 participants to date. Of this sample, 96.9% report experiencing depression and 79.7% endorse symptoms of mania or hypomania. Participants rated reducing stigma and alleviating symptoms as their 2 largest research priorities. Recruitment has been slower than expected. Recruiting a diverse sample has been challenging, and this impacts the Network's ability to conduct comparative effectiveness research studies. DISCUSSION: We discuss lessons learned from recruiting individuals with mood disorders to MoodNetwork, an innovative approach to conducting clinical trials. We identify and review 5 strategies for increasing enrollment as well as future directions.

Tambuyzer, E. et Van Audenhove, C. (2015). "Is perceived patient involvement in mental health care associated with satisfaction and empowerment?" Health Expect **18**(4): 516-526.

BACKGROUND: Patients increasingly assume active roles in their mental health care. While there is a growing interest in patient involvement and patient-reported outcomes, there is insufficient research on the outcomes of patient involvement. OBJECTIVE: The research questions in this study are as follows: 'To what extent is perceived patient involvement associated with satisfaction and empowerment?'; 'What is the nature of the relationship between satisfaction and empowerment?'; and 'To what extent are background variables associated with satisfaction and empowerment?'. We assumed that a higher degree of patient involvement is associated with higher satisfaction and empowerment scores and that satisfaction and empowerment are positively associated. DESIGN, SETTING AND PARTICIPANTS: Data were gathered using surveys of 111 patients of 36 multidisciplinary care networks for persons with serious and persistent mental illness. MAIN VARIABLES STUDIED AND MAIN OUTCOME MEASURES: Demographic characteristics, patient involvement and satisfaction were measured using a new questionnaire. Empowerment was assessed using the Dutch Empowerment Scale. Descriptive, univariate (Pearson's r and independent-samples t-tests), multivariate (hierarchical forced entry regression) and mixed-model analyses were conducted. RESULTS: The hypotheses of positive associations between patient involvement, satisfaction and empowerment are confirmed. The demographics are not significantly related to satisfaction or empowerment, except for gender. Men reported higher empowerment scores than did women. DISCUSSION AND CONCLUSIONS: Making patient involvement a reality is more than just an ethical imperative. It provides an opportunity to enhance patient-reported outcomes such as satisfaction and empowerment. Future research should focus on the nature of the association between satisfaction and empowerment.

Tanner, D. (2012). "Co-research with older people with dementia: experience and reflections." J Ment Health **21**(3): 296-306.

BACKGROUND: There is growing evidence that people with dementia want to participate in research and benefit from their involvement. However, little attention has been given to date to the potential to involve people with dementia as co-researchers, not just participants. AIMS: The paper discusses the implications for people with dementia of involvement in research as co-researchers. METHOD: Older people with dementia participated in planning the research methods, conducting interviews and making sense of the findings. RESULTS: The project found that it is possible to involve older people with dementia in a meaningful way in research processes and that both co-researchers and participants can benefit significantly from their

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participation. CONCLUSIONS: The project has wider implications for the development of participatory research with people with dementia and for interventions based on peer support.

Tavecchio, L., Van der Helm, P., Moonen, X., et al. (2019). "Participatory Peer Research in the Treatment of Young Adults With Mild Intellectual Disabilities and Severe Behavioral Problems." New Dir Child Adolesc Dev **2019**(167): 117-131.

This study provides an illustration of a research design complementary to randomized controlled trial to evaluate program effects, namely, participatory peer research (PPR). The PPR described in current study was carried out in a small sample (N = 10) of young adults with mild intellectual disabilities (MID) and severe behavioral problems. During the PPR intervention, control and feedback to individuals is restored by training them to become participant-researchers, who collaborate in a small group of people with MID. Their research is aimed at the problems the young adults perceive and/or specific subjects of their interest. The study was designed as a multiple case study with an experimental and comparison group. Questionnaires and a semistructured interview were administered before and after the PPR project. Results of Reliable Change Index (RCI) analyses showed a decrease in self-serving cognitive distortions in the PPR group, but not in the comparison group. These results indicate that PPR helps to compensate for a lack of adequate feedback and control, and in turn may decrease distorted thinking and thereby possibly later challenging behavior.

Taylor, P. J., et al. (2010). "The subjective experience of participation in schizophrenia research: a practical and ethical issue." J Nerv Ment Dis **198**(5): 343-348.

Mental health research may pose a risk to those who participate in it, especially for potentially vulnerable groups such as those diagnosed with schizophrenia. The current study aimed to investigate the subjective experience of research participation in this group. Seventy-nine individuals with diagnoses of schizophrenia spectrum disorders who had taken part in research looking at suicide were asked to provide feedback about their experiences. Responses were analyzed using qualitative and quantitative methods. Results indicate that negative feedback concerning participation was rare, occurring in 2.5% to 15.2% of responses. Positive feedback was more frequent, occurring in 45.6% to 60.8% of responses. Qualitative thematic analysis identified 5 key themes in participants' responses: Altruism, Value of being involved in research, Therapeutic effect, Enjoyable experience and Negative experiences. The results support the view that mental health research in this group can be ethically viable.

Thomas, E. C., Despeaux, K. E., Drapalski, A. L., et al. (2018). "Person-Oriented Recovery of Individuals With Serious Mental Illnesses: A Review and Meta-Analysis of Longitudinal Findings." Psychiatr Serv **69**(3): 259-267.

OBJECTIVE: Although there is significant literature examining changes over time in the functional recovery of people with serious mental illnesses, relatively little is known about the longitudinal nature of person-oriented recovery. The purpose of this review and meta-analysis is to synthesize findings pertaining to the study of person-oriented recovery constructs over time and concomitants of change. METHODS: Systematic searches up to February 2017 were conducted and were supplemented by hand-searching of reference lists and by contacting study authors. Twenty-three independent studies that included a sample of individuals with serious mental illnesses and that quantitatively measured person-oriented recovery, empowerment, or hope

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over at least two time points were included in the review. Of these, seven were randomized controlled trials that were included in the meta-analysis. Data were independently extracted by two reviewers. Aggregate effect sizes for person-oriented recovery outcomes were calculated, and individual, intervention, and methodological characteristics served as moderators in meta-regression analyses. RESULTS: The meta-analysis (N=1,739 participants) demonstrated that consumers experience greater (and sustained) improvement in person-oriented recovery outcomes when they are involved in recovery-oriented mental health treatment versus usual care or other types of treatment. Only type of intervention provider was a significant moderator; a study of an intervention that was delivered by both mental health professionals and peer providers demonstrated the greatest differences between treatment and control groups. CONCLUSIONS: Recovery-focused interventions, especially those that involve collaborations between mental health professionals and peer providers, may serve to foster increased recovery, hope, and empowerment among individuals with serious mental illnesses.

Townley, G. et Terry, R. (2018). "Highlighting the Way Forward: A Review of Community Mental Health Research and Practice Published in AJCP and JCP." Am J Community Psychol **61**(1-2): 10-21.

Articles published in the two most prominent journals of community psychology in North America, the American Journal of Community Psychology (AJCP) and Journal of Community Psychology (JCP), provide a clear indicator of trends in community research and practice. An examination of community psychology's history and scholarship suggests that the field has reduced its emphasis on promoting mental health, well-being, and liberation of individuals with serious mental illnesses over the past several decades. To further investigate this claim, the current review presents an analysis of articles relevant to community mental health (N = 307) published in the American Journal of Community Psychology (AJCP) and Journal of Community Psychology (JCP) from 1973 to 2015. The review focuses on article characteristics (e.g., type of article and methods employed), author characteristics, topic areas, and theoretical frameworks. Results document a downward trend in published articles from the mid-1980s to mid-2000s, with a substantial increase in published work between 2006 and 2015. A majority of articles were empirical and employed quantitative methods. The most frequent topic area was community mental health centers and services (n = 49), but the past three decades demonstrate a clear shift away from mental health service provision to address pressing social issues that impact community mental health, particularly homelessness (n = 42) and community integration of adults with serious mental illnesses (n = 40). Findings reflect both the past and present state of community psychology and suggest promising directions for re-engaging with community mental health and fostering well-being, inclusion, and liberation of adults experiencing serious mental health challenges.

Van den Steene, H., Van West, D. et Glazemakers, I. (2019). "[Potential of participatory action research for clients, professionals and researchers in mental healthcare]." Tijdschr Psychiatr **61**(5): 343-351.

In participatory action research (par), researchers, practitioners and the community engage in a research process together. This research approach has the potential to assist in bridging the research-practice gap by starting from practice needs and using joint expertise and experiences to enrich scientific knowledge, optimise clinical practice and empower stakeholders from different backgrounds.
 AIM: To discuss the potential benefits of par for clients, professionals and researchers in the field of mental healthcare.
 METHOD: Starting from the literature on par, fundamental characteristics and benefits of this research approach in the

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field of mental healthcare are described and illustrated with an example from practice.
RESULTS: par in mental healthcare can contribute to enriching prepositional and practical
knowledge, facilitate positive social change in care delivery, empower all stakeholders, and
ultimately make a significant contribution to the integration of research and practice.
CONCLUSION: par is valuable for clients, professionals and researchers in a variety of projects in
mental healthcare.

Vaisson, G. et Provencher, T. (2021). "User Involvement in the Design and Development of Patient
Decision Aids and Other Personal Health Tools: A Systematic Review." 272989x20984134.

BACKGROUND: When designing and developing patient decision aids, guidelines recommend
involving patients and stakeholders. There are myriad ways to do this. We aimed to describe
how such involvement occurs by synthesizing reports of patient decision aid design and
development within a user-centered design framework and to provide context by synthesizing
reports of user-centered design applied to other personal health tools. METHODS: We included
articles describing at least one development step of 1) a patient decision aid, 2) user- or human-
centered design of another personal health tool, or 3) evaluation of these. We organized data
within a user-centered design framework comprising 3 elements in iterative cycles:
understanding users, developing/refining prototype, and observing users. RESULTS: We included
607 articles describing 325 patient decision aid projects and 65 other personal health tool
projects. Fifty percent of patient decision aid projects reported involving users in at least 1 step
for understanding users, 35% in at least 1 step for developing/refining the prototype, and 84% in
at least 1 step for observing users' interaction with the prototype. In comparison, other personal
health tool projects reported 91%, 49%, and 92%, respectively. A total of 74% of patient decision
aid projects and 92% of other personal health tool projects reported iterative processes, both
with a median of 3 iterative cycles. Preliminary evaluations such as usability or feasibility testing
were reported in 66% of patient decision aid projects and 89% of other personal health tool
projects. CONCLUSIONS: By synthesizing design and development practices, we offer evidence-
based portraits of user involvement. Those wishing to further align patient decision aid design
and development with user-centered design methods could involve users earlier, design and
develop iteratively, and report processes in greater detail.

van Weeghel, J., van Zelst, C., Boertien, D., et al. (2019). "Conceptualizations, assessments, and
implications of personal recovery in mental illness: A scoping review of systematic reviews and meta-
analyses." Psychiatr Rehabil J **42**(2): 169-181.

OBJECTIVE: Recovery, defined as a personal process of living with mental illness, has become a
prominent concept in mental health care. We aimed to map the state of the art of
conceptualizing recovery, its promoting and impeding factors, recovery-oriented practice, and
the assessment of recovery. METHOD: A scoping review of systematic reviews and meta-
analyses was performed. Systematic searches were conducted, supplemented with hand-
searching in reference lists. RESULTS: Of 228 articles that were identified and 33 that were
reviewed, a total of 25 were included. This review showed that the CHIME conceptual
framework for personal recovery is widely endorsed, containing the elements of connectedness,
hope and optimism, identity, meaning in life, and empowerment. Although personal recovery
first and foremost starts from individual preferences, the CHIME framework should be adapted
according to culture and unique population characteristics. "Difficulties and trauma" should be
added, and the person's choice, risk taking, and coping with challenges should be emphasized.

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Barriers to recovery are stigma and negative effects of mental health services and medication. Facilitators of recovery include spirituality, personal agency, and social support. Recovery-focused interventions, in which peer providers are involved, enhance recovery, hope, and empowerment. For assessing recovery outcomes, multiple instruments are accepted as methodologically sound. CONCLUSIONS: Personal recovery is conceptualized as complementary to clinical recovery and represents processes rather than outcomes. Additional work is needed to bridge the gap between the concept of recovery-oriented practice and routinely provided interventions. A broad framework of recovery is needed, and more research is needed into the working mechanisms of personal recovery processes. (PsycINFO Database Record (c) 2019 APA, all rights reserved).

Viksveen, P., Bjonness, S. E., Berg, S. H., et al. (2017). "User involvement in adolescents' mental healthcare: protocol for a systematic review." BMJ Open **7**(12): e018800.

INTRODUCTION: User involvement has become a growing importance in healthcare. The United Nations state that adolescents have a right to be heard, and user involvement in healthcare is a legal right in many countries. Some research provides an insight into the field of user involvement in somatic and mental healthcare for adults, but little is known about user involvement in adolescents' mental healthcare, and no overview of the existing research evidence exists. METHODS AND ANALYSIS: The aim of this systematic review is to provide an overview of existing research reporting on experiences with and the effectiveness and safety issues associated with user involvement for adolescents' mental healthcare at the individual and organisational level. A systematic literature search and assessment of published research in the field of user involvement in adolescents' mental healthcare will be carried out. Established guidelines will be used for data extraction (Cochrane Collaboration guidelines, Strengthening the Reporting of Observational studies in Epidemiology and Critical Appraisal Skills Programme (CASP)), critical appraisal (Cochrane Collaboration guidelines and Pragmatic-Explanatory Continuum Indicator Summary) and reporting of results (Preferred Reporting Items for Systematic reviews and Meta-Analyses, Consolidated Standards of Reporting Trials and CASP). Confidence in the research evidence will be assessed using the Grading of Recommendations Assessment, Development and Evaluation approach. Adolescents are included as coresearchers for the planning and carrying out of this systematic review. This systematic review will provide an overview of the existing research literature and thereby fill a knowledge gap. It may provide various stakeholders, including decision-makers, professionals, individuals and their families, with an overview of existing knowledge in an underexplored field of research. ETHICS AND DISSEMINATION: Ethics approval is not required for this systematic review as we are not collecting primary data. The results will be published in a peer-reviewed journal and at conference presentations and will be shared with stakeholder groups.

Villani, M. et Kovess-Masféty, V. (2018). "[Peer support programs in mental health in France: Status report and challenges]." Encephale **44**(5): 457-464.

OBJECTIVES: Recovery is a process through which people experiencing mental illness learn to live with their disorder and reach social insertion and citizenship. This positive approach focuses on a person's competencies and strengths rather than on the symptoms. Within this philosophy, peer support has been unevenly developing in mental health services worldwide with roots in the South-American social programs for homeless people and in the American recovery circles in the field of addiction. Therapeutic efficiency of peer support has been proven by several studies

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including a control group, as being at least as good as traditional services and even better in some specific areas such as reduction of need for emergency services and ability to reach "difficult" patients. The integration of former psychiatric services users in mental health services can take several forms, from the participation to scientific research studies to the direct involvement in a professional team at mental health facilities. In this context, our research aims to sum up the situation in France in comparison with other countries. METHODS: We conducted a worldwide literature review in English and in French on peer support experiences and policies in mental health services, using medical and psychological databases (PsycInfo, PsycArticles, SantéPsy, Cairn, Medline, Wiley Interscience and PubPsych) on a recent period: 2005-2016. In total, 32 relevant scientific papers have been included in our research. In some cases, we have also used official reports, blogs, Internet sites, and mass media articles when they were relevant. RESULTS: Our results show that this movement has been long to develop in France, with controversies having been raised since the beginning on the role that peers should play and confusion with existing social integration programs in the associative sector. Drawing inspiration from the Canadian model, a recent "peer mentor" initiative has been analyzed after 2 years of existence: many benefits for services users such as the optional aspect of this care process, a more authentic therapeutic relationship, a less normative frame, an active partnership, and a more optimistic philosophy aiming to make "small steps" towards improvement have been reported. Health professionals and peer mentors themselves have found benefits during the process. However, several limits such as difficulties to find a place with regards to the psychiatric team and difficulties to take advantage of the peer specificity, resulting in a significant attrition of the number of peer mentors, could be observed. A few other important initiatives focused on social insertion and using the help of professional peer support have been developed in recent years, but they seem to have encountered the same issues about positioning themselves both in terms of day-to-day integration in the professional environment and in the job title given by institutions which rarely corresponds to their experience and specificity. In addition, it remains difficult to obtain reliable information, as only a few papers have been published on this matter. Also, while some evaluation studies are currently being carried out, independent quantitative studies of the few running programs seem to lack in this field. CONCLUSIONS: In our presentation, taking into account the difficulties that were raised in French programs and the lessons of practical experiences at work in other countries, we propose recommendations for larger and more effective implementations of peer support programs in France. As this new kind of care is emerging and seems promising in terms of benefits for not only the users but also the peer supporters and the teams of health professionals, we also insist on the need for a systematic scientific and objective evaluation of the programs.

Waite, J., Poland, F. et Charlesworth, G. (2019). "Facilitators and barriers to co-research by people with dementia and academic researchers: Findings from a qualitative study." Health Expect **22**(4): 761-771.

BACKGROUND: Public and patient involvement (PPI) is now established in dementia research. Barriers and facilitators to engagement from family carers and people in early stages of dementia have been explored. However, specific barriers and facilitators to co-research with people with dementia have not previously been investigated. OBJECTIVE: To discover the facilitators of, and barriers to, involving people with dementia as co-researchers, from the perspectives of people with dementia, gatekeepers (family caregivers, ethics committee members, service providers) and researchers. DESIGN: Thematic analysis of data from individual interviews about the co-research experience. RESULTS: Four themes emerged from interviews with 19 participants (five people with dementia): "getting one's head round it" (assumptions

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about research and dementia; different forms of language); practicalities (eg transport; accessibility of communication); "this feeling of safety" (perceptions of danger, protectiveness and opportunities for building trust); and motivations ("making a difference" and "keeping doing"). CONCLUSIONS: Findings both replicate and extend previous knowledge on PPI in dementia. Cognitive capacity of potential co-researchers with dementia is only a part of the picture, with attitudes and expectations of researchers, gatekeepers and people with dementia also forming barriers. Researcher education, adequate resourcing, and both creativity and flexibility are needed to support recruitment of co-researchers with dementia and to enable meaningful co-research.

Walsh, J. et Boyle, J. (2009). "Improving acute psychiatric hospital services according to inpatient experiences. A user-led piece of research as a means to empowerment." Issues Ment Health Nurs **30**(1): 31-38.

This paper has been undertaken by people with experience with mental health issues and mental health care systems. The aim of the research was to explore psychiatric inpatients' strategies for coping with mental ill health and in what ways acute inpatient psychiatric hospital services are facilitative to the individual attempting recovery. Ten focus groups were facilitated and data were analysed through systematic content analysis. Findings revealed that the main areas of concern for inpatients were: information, communication, relationships, activities, self-help, patient involvement in care treatment plans, and the physical environment. The authors also make a case to improve the status of user-led research as a means to understand the needs of mental health service users.

Wells, K., et al. (2004). "Bridging community intervention and mental health services research." American Journal of Psychiatry **161**(6): 955-963.

Werner-Seidler, A. et Shaw, F. (2019). "The Social and Emotional Impact of Involving Individuals With Mental Illness in the Research Process." Qual Health Res **29**(11): 1634-1640.

There is a need to involve individuals with a lived experience in health and medical research. Some organizations have developed mechanisms to seek the input of people with a lived experience. However, there are few examples of qualitative research into the impacts of participation. In this study, we investigate the social and emotional impact of participation on individuals, as well as the perceived impact on the organization, in an advisory panel at an Australian mental health research institute. In-depth qualitative interviews were conducted with 50% of the participants on the panel to understand how they conceptualized their involvement. Participants became invested in the organization and their role within it, and found it personally valuable to access diverse perspectives and discuss mental health outside a treatment context. These findings suggest that participating in the research process is beneficial to individuals with a lived experience of mental illness.

White, S., Foster, R., Marks, J., et al. (2020). "The effectiveness of one-to-one peer support in mental health services: a systematic review and meta-analysis." BMC Psychiatry **20**(1): 534.

BACKGROUND: Peer support is being introduced into mental health services internationally, often in response to workforce policy. Earlier systematic reviews incorporate different modalities of peer support (i.e. group and one-to-one), offer inconsistent evidence of

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effectiveness, and also indicate substantial heterogeneity and issues of quality in the evidence base at that time. An updated review, focussed on one-to-one peer support, is timely given current policy interest. This study aims to systematically review evidence for the effectiveness of one-to-one peer support interventions for adults using mental health services, and to explore heterogeneity in peer support interventions. METHOD: We searched MEDLINE, PsycINFO, Embase, CINAHL and Cochrane databases from inception until 13 June 2019. Included studies were assessed for risk of bias, and meta-analyses conducted where multiple trials provided usable data. RESULTS: Twenty-three studies reporting nineteen trials were eligible, providing data from 3329 participants. While seven trials were of low to moderate risk of bias, incomplete reporting of data in many studies suggested bias in the evidence base. Peer support interventions included peer workers in paraclinical roles (e.g. case manager), providing structured behavioural interventions, or more flexible support for recovery. Meta-analyses were conducted for eleven outcomes, with evidence that one-to-one peer support may have a modest positive impact on self-reported recovery and empowerment. There was no impact on clinical symptoms or service use. Analyses of heterogeneity suggest that peer support might improve social network support. CONCLUSIONS: One-to-one peer support in mental health services might impact positively on psychosocial outcomes, but is unlikely to improve clinical outcomes. In order to better inform the introduction of peer support into mental health services, improvement of the evidence base requires complete reporting of outcome data, selection of outcomes that relate to intervention mechanisms, exploration of heterogeneity in the implementation of peer support and focused reviews of specific types of one-to-one peer support. TRIAL REGISTRATION: Prospero identifier: CRD42015025621 .

Wilson, C., et al. (2010). "A potential model for the first all Wales mental health service user and carer-led research group." J Psychiatr Ment Health Nurs **17**(1): 31-38.

This paper will inform mental health service users and carers on how a University in Wales established a service user and carer-led research group. * The group's primary aim will be to undertake its own service user and carer-led research projects. * Mental health service users have undergone empowerment and research training at a University in Wales. This is an important initiative because it is the first service user and carer-led research group in Wales. * This paper is co-authored by a mental health service user and includes transcripts of service users' stories written in their words. Abstract Service user and carer involvement in research has been gaining momentum in recent years. However, this involvement to date has primarily been as research respondents or 'subjects' in research studies. A group of mental health service users at a University in Wales underwent empowerment and research training to enable them to become active participants in the research process; this training was a necessary step to equip mental health service users with the skills to become independent researchers and to carry out service user-led research. We included transcripts from mental health service users on their views of the empowerment and research training received. We are not reporting, in this paper, on the findings from a research study rather it aims to inform readers how a service user and carer-led research group has been established in Wales. The group has two purposes: (1) to train service users in research methodologies, and thus for them to gain essential research skills; and (2) to undertake their own service user and carer-led research projects thereby implementing the research skills they have acquired from the training. The latter is a primary aim of the group; a future paper will report on its development.

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Winness, M. G., et al. (2010). "Service users' experiences with help and support from crisis resolution teams. A literature review." J Ment Health **19**(1): 75-87.

> BACKGROUND: Services for crisis resolution provided by home treatment teams are recent developments in the mental health care scene. There is a lack of systematized reviews in the service users' responses to these services. AIM: To systematize the existing knowledge regarding the service users' experiences with crisis resolution and home treatment (CR/HT) teams in order to explore ways to develop this form of service further. METHOD: A systematic review of the periodical literature and research reports on CR/HT was carried out for the period from January 1995 to January 2009. RESULTS: A total of 13 papers, one RCT review and two reports were identified, including both qualitative and quantitative studies. Although these studies provided few in-depth details, three major themes as the characteristics of CR/HT teams are extracted as: (a) access and availability, (b) being understood as "normal" human beings, and (c) dealing with crises in an everyday life context. CONCLUSIONS: The findings suggest that the key positive characteristics of help in crisis situations are intrinsically tied to the values and principles undergirding CR/HT services. The commitment to community-based services, the philosophy of partnership, and user-empowerment seem to the base from which these three themes of positive experiences emerged.

Wolff, T. (2014). "Community psychology practice: expanding the impact of psychology's work." Am Psychol **69**(8): 803-813.

> This article introduces the reader to community psychology practice by defining the field and its key principles and then illustrating through brief case stories what community psychology practice looks like in various employment settings. An exploration of the development of the field includes a review of the competencies of community psychology practice. Finally, the emerging opportunities for community psychology practice for psychologists are outlined. Well-publicized issues such as health disparities give psychologists an opportunity to bring social problems such as racism, sexism, homophobia, and income inequality to the forefront and to create community-wide efforts to improve the ways in which people live. Community psychology practice offers psychologists a format and a set of competencies for moving forward on this work by focusing on approaches that are ecological, community centered, population based, preventive, focused on systems change and empowerment, and multidisciplinary and that bring those most affected by the issues to the heart of the decision making.

Woodall, A., et al. (2010). "Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers?" BMC Psychiatry **10**: 103.

> BACKGROUND: It is well established that the incidence, prevalence and presentation of mental disorders differ by gender, ethnicity and age, and there is evidence that there is also differential representation in mental health research by these characteristics. The aim of this paper is to a) review the current literature on the nature of barriers to participation in mental health research, with particular reference to gender, age and ethnicity; b) review the evidence on the effectiveness of strategies used to overcome these barriers. METHOD: Studies published up to December 2008 were identified using MEDLINE, PsycINFO and EMBASE using relevant mesh headings and keywords. RESULTS: Forty-nine papers were identified. There was evidence of a wide range of barriers including transportation difficulties, distrust and suspicion of researchers, and the stigma attached to mental illness. Strategies to overcome these barriers included the

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use of bilingual staff, assistance with travel, avoiding the use of stigmatising language in marketing material and a focus on education about the disorder under investigation. There were very few evaluations of such strategies, but there was evidence that ethnically matching recruiters to potential participants did not improve recruitment rates. Educational strategies were helpful and increased recruitment. CONCLUSION: Mental health researchers should consider including caregivers in recruitment procedures where possible, provide clear descriptions of study aims and describe the representativeness of their sample when reporting study results. Studies that systematically investigate strategies to overcome barriers to recruitment are needed.

Wu, A. W., Connors, C. et Everly, G. S., Jr. (2020). "COVID-19: Peer Support and Crisis Communication Strategies to Promote Institutional Resilience." Ann Intern Med **172**(12): 822-823.

Caring for patients with the novel coronavirus infection is placing great stress on health care systems and health care workers. On the basis of their experiences responding to other pandemics, the authors summarize lessons learned and offer some best practices for facilitating organizational resilience and supporting health care workers during the COVID-19 pandemic.

Youn, S. J., Valentine, S. E., Patrick, K. A., et al. (2019). "Practical solutions for sustaining long-term academic-community partnerships." Psychotherapy (Chic) **56**(1): 115-125.

The science-practice gap in the treatment of mental health is most pronounced in community settings, where clients with the highest needs often receive their care. Implementation science and community-based participatory research strategies aim to effectively address this gap by establishing partnerships that focus on scientifically rigorous, as well as clinically and socially relevant, research. Despite significant benefits, the community-based participatory research implementation framework has a unique set of challenges. The current article describes evidence-supported implementation strategies that were deployed to address various barriers to the implementation and long-term sustainability of an innovative cognitive-behavioral theory (CBT) life skills program identified during a feasibility trial. Through the committed work of an established partnership between a community-based nonprofit organization and researchers, barriers and the strategies for mitigating these obstacles were jointly identified. Specific challenges included fidelity (variability in staff's CBT competency and delivery), sustainability, and the cost of guideline implementation (data collection, time, and resources) of the CBT curriculum. We also provide details on the partnership's solutions to these major obstacles, including the development of an intensive 3-month training and coaching phase. The results of this rigorous training suggest improvement in staff's overall CBT competency and fidelity, increased participant engagement in the CBT curriculum, and enhanced data-collection procedures; yet, sustainability difficulties remained. General recommendations for long-term community research partnerships include early organizational buy-in; comprehensive needs assessments, including the organization's research building capacity; and sustained training and coaching models. (PsycINFO Database Record (c) 2019 APA, all rights reserved).

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Base de données et bibliographies thématiques sur la santé mentale.
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https://www.ascodocpsy.org/santepsy/index.php?lvl=more_results&mode=extended

Atlas de la santé mentale
L'Atlas de la santé mentale en France constitue une base de données territorialisées. Il rassemble plus de 350 indicateurs pouvant être mobilisés dans l'élaboration et le suivi des diagnostics de santé partagés des projets territoriaux en santé mentale.

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Firah
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Fondation Fondamental
Fondation de coopération scientifique dédiée à la lutte contre les maladies malades les plus graves.

Irdes
Un des axes de recherche de l'Irdes porte sur la santé mentale.
Les publications sont en ligne sur le web à la rubrique : Psychiatrie et santé mentale.
Une bibliographie thématique porte sur la recherche participative en santé mentale. Elle est consultable sous la rubrique « Synthèses & Bibliographies ».

Psycom
Le Psycom est un organisme public d'information, de formation et de lutte contre la stigmatisation en santé mentale. Il aide à mieux comprendre les troubles psychiques, leurs traitements et l'organisation des soins psychiatriques. Il édite des documents d'information à l'intention des patients et de leurs proches, des professionnels et du grand public. Il publie une lettre d'informations hebdomadaire.

Psydoc
Site géré par la Fédération Française de Psychiatrie et alimenté par des collaborations diverses. On accède aux rubriques suivantes : liste des associations membres de la FFP, bases de données interactives, plates-formes scientifiques (ensemble structuré d'informations dans un domaine particulier, à partir de références bibliographiques, d'articles et d'adresses web), revues en psychiatrie, colloques, cyberconférences, conférences de consensus-RPC-RMO, formations, recherche en psychiatrie, listes de diffusion, questions d'usagers, sélection de sites.

SFSP
Dossier documentaire sur la santé mentale : plans, programmes, lois, avis, rapports... (2018)

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Unafam
Cette association concentre son action au profit de l'entourage des personnes vivant avec des troubles psychiques sévères, essentiellement des personnes atteintes de schizophrénie, de troubles bipolaires, de dépressions sévères, de psychoses graves et de troubles obsessionnels compulsifs. Depuis plus récemment, l'Unafam reçoit les parents d'enfants et d'adolescents ayant des troubles psychologiques, des troubles psychiques ou des troubles du comportement. Elle publie la revue *Regards*.

International

OCDE
Nombreuses publications sur la santé mentale dans les pays de l'OCDE : épidémiologie, coût, politique psychiatrique, ainsi que la relation entre santé mentale et emploi avec la série des *Mental health at work* ou le Health Mental Health Framework.

OMS
Publications sur la politique de prévention de la santé mentale dans le monde : prévention du suicide, atlas, plan d'action… L'ensemble des publications sur cette thématique est à cette url : https://www.who.int/mental_health/publications/fr/

WHO Mindbank
Plateforme de partage d'informations de l'OMS sur la santé mentale, l'abus de substances psychoactives, le handicap et les droits de l'homme. Elle permet l'accès aux politiques nationales menées dans les différents domaines listés ci-dessus, ainsi qu'aux principaux rapports de l'OMS et des Nations Unis.

DOSSIERS DOCUMENTAIRES

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