

**How can we do better in improving lives of people with severe mental health problems?**

***The case for a change in research priorities***

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# The outcomes of psychosis

Pooled meta-analysis of long-term psychosis studies over 50 years

- Remission rate after first episode has improved in N America, not in Europe
- Recovery rate has not improved (pooled estimate: 38% have made a good recovery at 7 yrs) **Lally et al. 2017**
- Bipolar – less data but similarly no signs of improvement in last few decades

## The British Journal of Psychiatry

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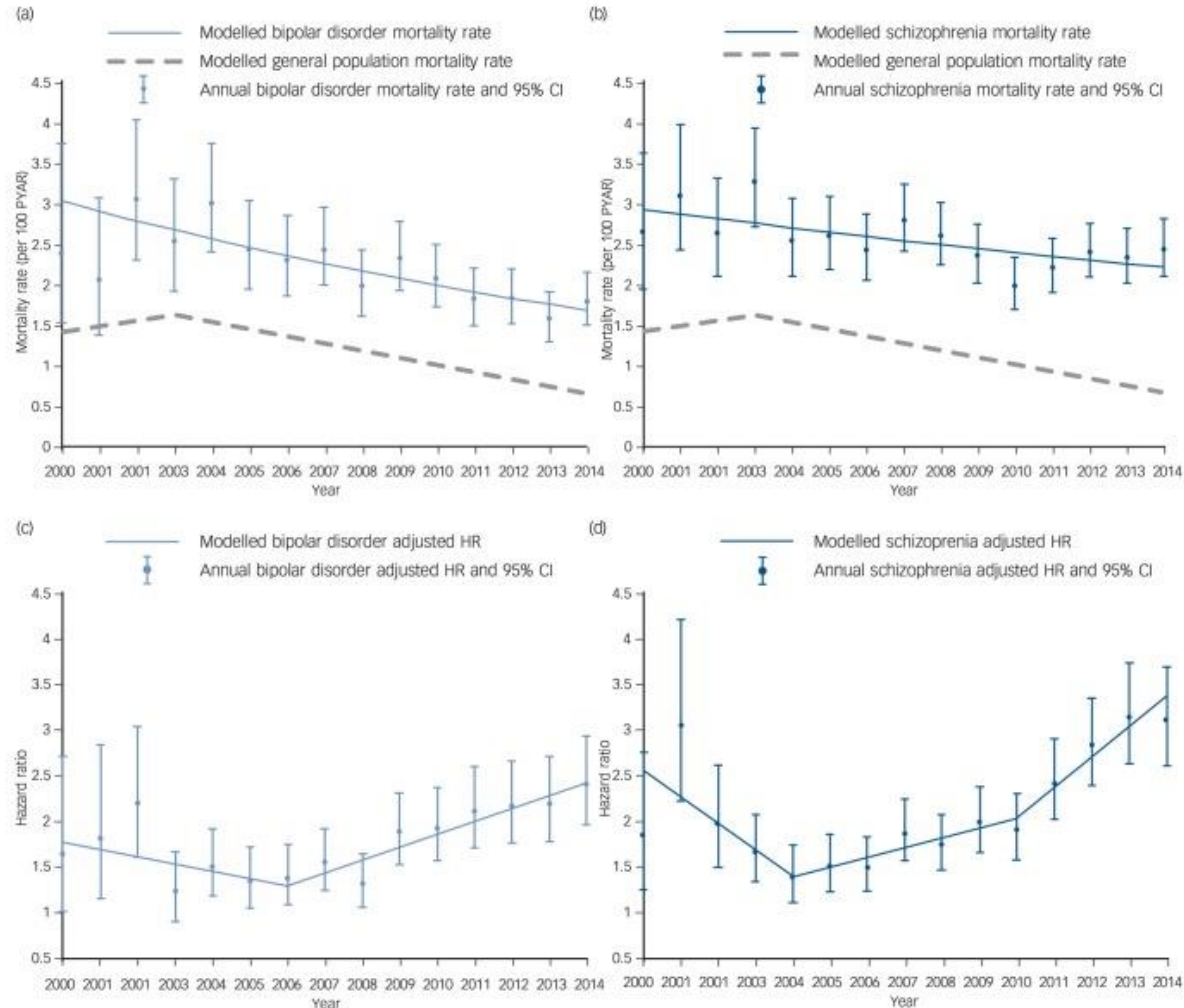
### Remission and recovery from first-episode psychosis in adults: systematic review and meta-analysis of long-term outcome studies

John Lally <sup>(a1)</sup>, Olesya Ajnakina <sup>(a2)</sup>, Brendon Stubbs <sup>(a3)</sup>, Michael Cullinane <sup>(a4)</sup> ... 

<https://doi.org/10.1192/bjp.bp.117.201475> Published online: 02 January 2018

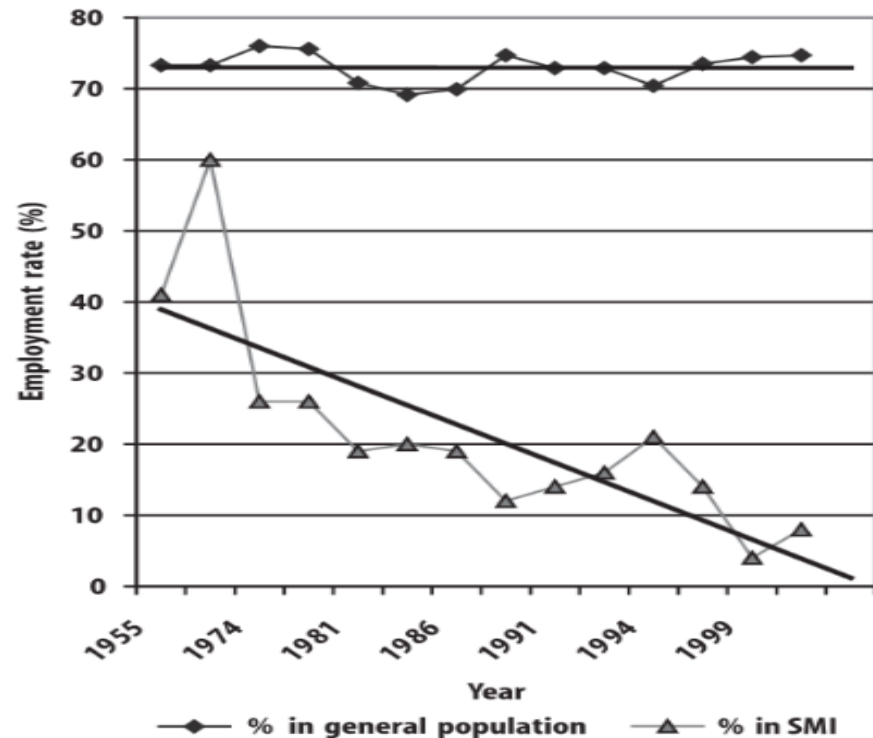
# A widening mortality gap

Hayes et al  
2000-14  
Increasing gap  
between people  
with psychosis  
or bipolar vs.  
general  
population



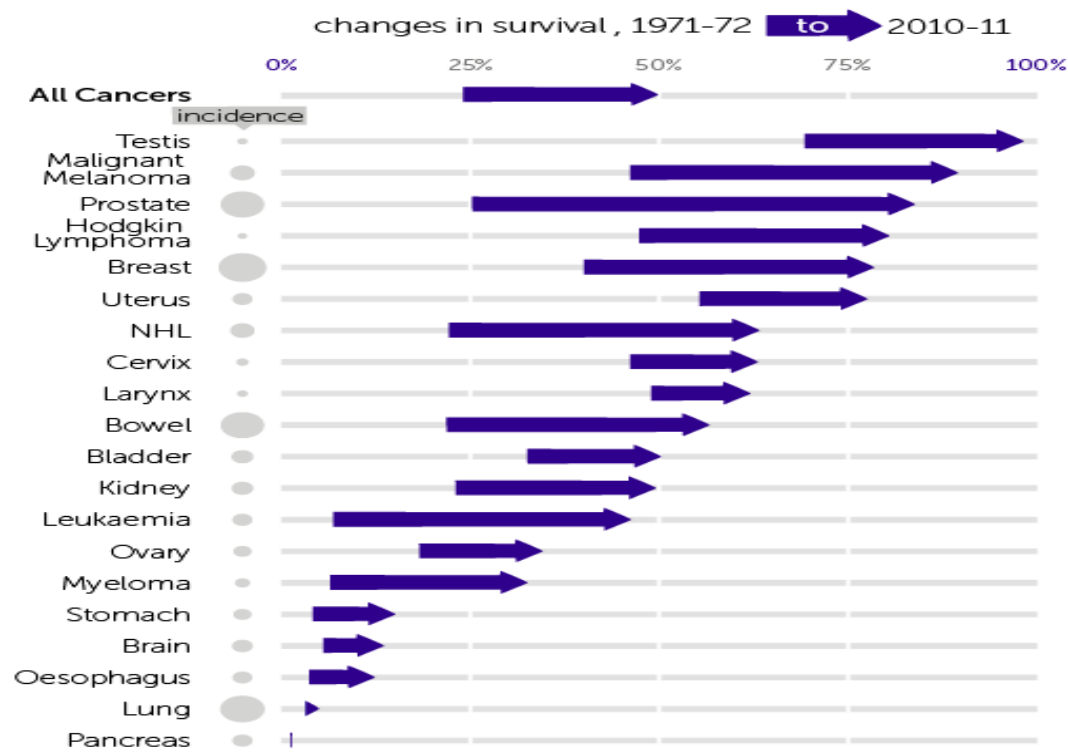
# Employment rates in psychosis in the UK

Marwaha and Johnson 2004



**Fig. 1** Employment in the UK general population compared with employment in people with schizophrenia from UK studies

# Cancer survival changes 1970-2010



So....

- Not much evidence of progress in achieving substantial change in mental health outcomes for people with severe mental health problems
- Many common physical long-term conditions have seen steady progress
- Outcomes may still be better in countries with little mental health care (*but disputed* )

# Why have we not done better?

- **Neuroscience/Pharmacology:** Still investing and waiting for the great leap forward
- **Psychology:** Small benefits so far from interventions that have been hard to implement widely
- **Innovative service models:** Benefits from EI, but short term. Changing service organisation may not sufficiently change content of care.
- **The implementation gap:** translation of positive findings to practice often very slow/doesn't occur
- **Social determinants of mental health:** hard to mitigate impacts of austerity, inequality etc.
- **Problems of injustice/lack of compassion in services**
- **Stigma/lack of equity with physical health**

## A more positive note



The move out of the large psychiatric hospitals probably should be seen as a positive achievement in the past half century



# What do service users tell us we should focus on?

Findings from two decades of service user involvement in research and service planning:

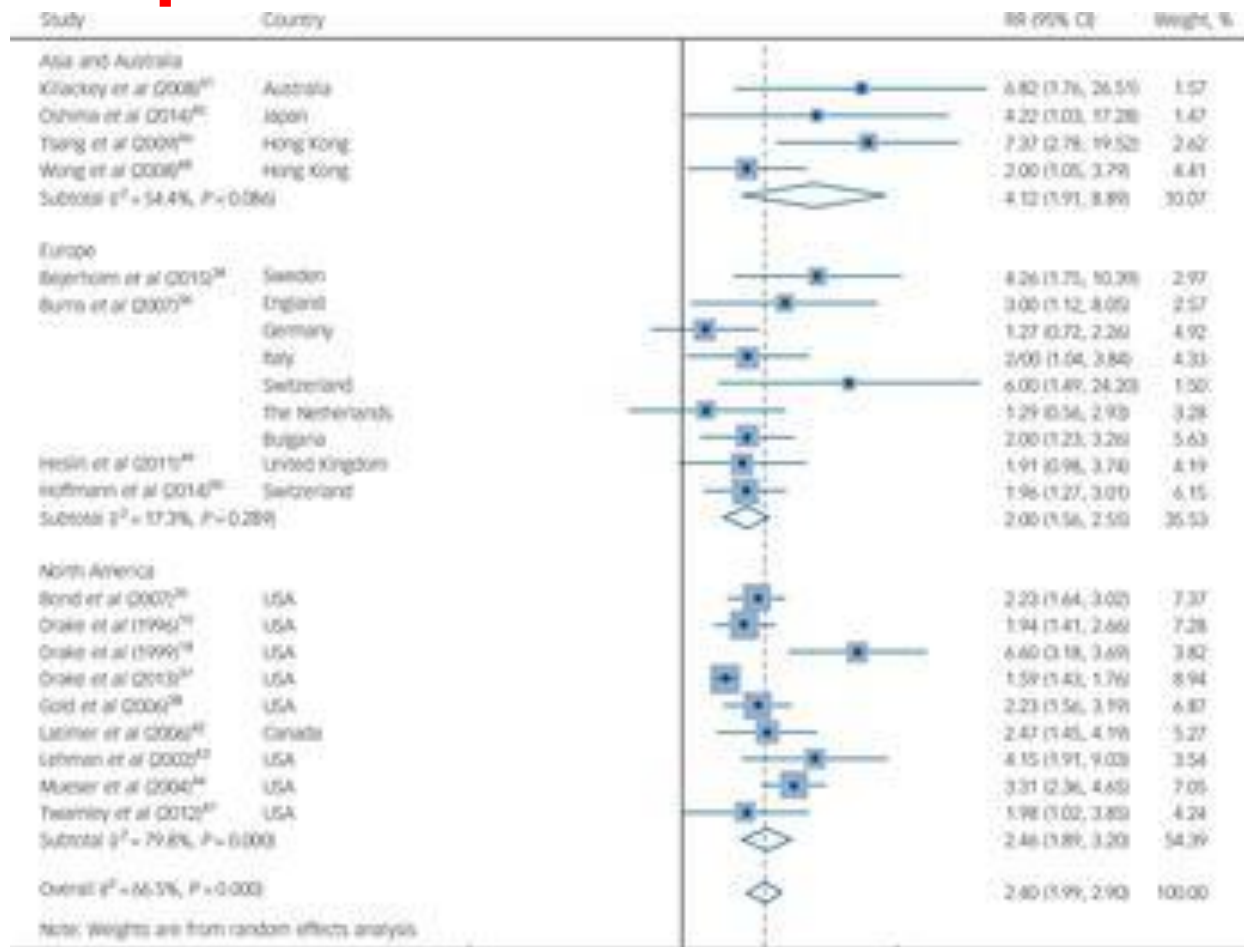
- Clinicians – often focus on risk and symptoms (especially positive)
- Service users more often concerned with autonomy, relationships, well-being, social problems, challenges in daily living

Many treatment trials – symptoms, relapse, risk events as priorities

# How could researchers contribute more to improving outcomes?

- Let's engage with people with lived experience – we haven't done well by leaving them out.
- Enriching content and quality of care *throughout* services a priority...
- E.g. **Community mental health teams** – not much consensus/evidence on content of continuing care provided by care coordinators.
- **Three potential priorities** for mental health researchers (and service planners), focusing on support in everyday life and on social targets
  - **A. Vigorous efforts to implement with high fidelity well-developed psychosocial interventions that already have a clear evidence base.**  
E.g. supported employment
  - **B. Refining, working out how to translate to routine care interventions that are already available and promising e.g.** supported self-management
  - **C. Developing new intervention strategies addressing social targets e.g.** loneliness

# A. Individual placement and support - **an example of an intervention requiring implementation**



Modini et al 2016

2.4 times increased rate of competitive employment IPS: vs. vocational rehab

Robust across time and country

Little justification for not offering it to all (though without coercion to take unsuitable/unwanted work

# The implementation gap

- Widespread failure across healthcare to put in practice interventions found to be effective & cost-effective
- Appears especially great in mental health
- A well-known example: family intervention to reduce expressed emotion in schizophrenia - delivered to only a small minority despite vast evidence base from 1970s on.
- **Digital interventions** – a current major implementation challenge
- Other interventions e.g. crisis resolution team care do get implemented, but with **low fidelity**.
- Little expectation that when research shows an intervention to be effective it will then become widely available in practice.

# The growing discipline of Implementation Science

Aiming for knowledge that generalises beyond a specific intervention

Questions like:

- What obstacles prevent take-up of effective interventions?
- What are the organisational and attitudinal factors that influence implementation?
- What strategies are effective in overcoming research-to-practice gap quickly?

Potentially crucial insights for translating evidence-based strategies into practice

Still need to successfully implement implementation science!



## B. Self-management as an intervention to be refined and tested for use across NHS

*Supporting self-management is inseparable from the high-quality care for Long Term Conditions.*

*Commissioners and health-care providers should promote a culture of actively supporting self-management as a normal, expected, monitored and rewarded aspect of care. Further research is needed to understand how health service managers and staff can achieve this culture change in their health-care organisations.*

Trish Greenhalgh  
2014



# Self-management

- Relevant across all conditions, especially long term ones.
- *the tasks . . . individuals must undertake to live with one or more chronic conditions . . . [including] . . . having the confidence to deal with medical management, role management and emotional management of their conditions* Greenhalgh, 2014
- Effectiveness established for most LTCs where well investigated.
- Tends work best in LTCs when **supported** - integrated with services
- In mental health frequent components include:
- Psychoeducation about mental health problems and treatment options (supporting informed decisions about care)
- Recognition of early warning signs of relapse and development of a relapse prevention plan
- Coping skills for dealing with persistent symptoms
- Working towards individualised recovery goals

## **Melanie Lean et al.: Meta-analysis of self-management intervention in mental health (under review)**



- Thirty-seven randomised controlled trials meeting criteria were identified, of which 35 provided usable data for meta-analysis.
- From the meta-analysis, self-management interventions conferred benefits in terms of reducing symptoms and length of admission, and improving recovery, hope, functioning and quality of life both at the end of treatment and at follow up.
- Most effect sizes small to medium.



## THE LANCET

ARTICLES | [VOLUME 392, ISSUE 10145, P409-418, AUGUST 04, 2018](#)

## Peer-supported self-management for people discharged from a mental health crisis team: a randomised controlled trial

[Prof Sonia Johnson, DM](#)   • [Danielle Lamb, PhD](#) • [Louise Marston, PhD](#) • [Prof David Osborn, PhD](#) • [Oliver Mason, PhD](#) • [Claire Henderson, PhD](#) • et al. [Show all authors](#)

[Open Access](#) • Published: August 04, 2018 • DOI: [https://doi.org/10.1016/S0140-6736\(18\)31470-3](https://doi.org/10.1016/S0140-6736(18)31470-3) •



## Summary

Background

Summary

Introduction

# CORE study: rationale for self-management in crisis teams

- High rates of readmission to acute care after crisis resolution team (CRT) episode (approx 50% in 1 year – Hayes et al 2016)
- Some evidence to support self-management (including relapse prevention, crisis planning, setting recovery goals)
- Self management approaches such as relapse prevention not well implemented in practice
- Peer support – highly favoured, but no clearly evidence-based model for severe mental health problems

Thus peer-supported self-management identified as most promising model to test for preventing relapse after crisis

# **CORE study (NIHR Programme Grants for Applied Research)- design**

**Phase 1: Literature reviews, qualitative interviews with service users, friends and family, clinicians -**

**Phase 2: Intervention planning, feedback**

**Phase 3: Uncontrolled feasibility study – 11 participants, followed by qualitative interviews**

**Phase 4: Pilot trial – 40 participants**

**Phase 5: Multicentre randomised controlled trial (6 Trusts)**

# Peer supported self-management intervention

- Assigned a peer support worker (PSW) on discharge from crisis team and a self-management workbook (based on resources from Julie Repper and Rachel Perkins)
- Ten hour-long sessions with PSW, within three months of baseline
- Unstructured and structured time available
- PSWs supervised in groups weekly by clinicians within CRTs, individually every few weeks. Also access to peer mentor
- Qualitative interviews with participants, peer support workers, clinicians to refine intervention in early phases

*“It was more being with a human, not with someone who learned things from the book. Because I am an intelligent person; I read lots of books and all that, but sometimes it’s actually better to learn from a person who learnt from life, who went through things in life and experienced them organically, not just memorised them or something”*

# Self-management booklet (experimental and control groups)

- 1. Moving on after a crisis (re-establishing social networks and community functioning; identifying values, responsibilities and activities)
  - 2. Keeping well (developing sense of identity; setting and keeping routines; identifying constructive behaviours and avoiding destructive ones)
  - 3. Managing ups and downs (identifying triggers, early warning signs; action plans)
  - 4. Goals and dreams (planning strategies; sources of information and support)
- Control group participants sent booklet throughposts

# Randomised controlled trial

- Recruited from 6 trusts – mixture of urban and rural settings
- 440 total (40 from pilot)
- Inclusion criteria:
  - >1 week on CRT caseload
  - Understanding English
  - <1 month from discharge to study entry
  - Capacity to consent
- 50% psychosis/bipolar disorder
- Peer delivered self management support vs. booklet only

## Results

Primary outcome: readmission to an acute service within 1 year:

Experimental group: 64/218 (29%)

Control group: 83/216 (38%)

**Odds ratio: 0.66[0.43, 0.99]<sup>a</sup>**

Outcomes	Control group		Intervention group		Coefficient* [95% CI]
	n/N or median	% or (IQR)	n/N or median	% or (IQR)	
<b>Secondary outcomes</b>					
Satisfaction with care	26	(20, 29)	26	(23, 30)	1.96[1.03, 2.89] <sup>b</sup>
Time (days) to first readmission	86	(43, 180)	112	(42, 242)	0.71[0.52, 0.97]
Days in acute care in 1 yr	0	(0, 24)	0	(0, 26)	1.01[0.76, 1.36]
Self-management skills	50	(8)	51	(8)	1.06[-0.49, 2.61] <sup>b</sup>
Self-rated recovery	55	(16)	57	(16)	2.90[0.08, 5.72] <sup>b</sup>
Symptom severity	41	(12)	39	(12)	-1.08[-3.17, 1.01] <sup>b</sup>
Loneliness	22	(20, 24)	22	(19, 24)	0.03[-0.66, 0.73] <sup>b</sup>
Social network size	12	(6)	12	(5)	-0.06[-1.02, 0.90] <sup>b</sup>



## Picture from our study

- **Positive result:** experimental hypothesis of an effect on the primary outcome confirmed
- **Mixed intervention:** not clear what critical ingredients are
- Combined test of self-management and peer support
- Considerable use of **recovery workbook** among controls makes picture less clear
- **No really clear effect on symptoms, recovery etc.** (though some evidence of difference in satisfaction) – maybe measures too global
- **Qual evidence** – seemed to work well for both peers and recipients
- **Digital version of workbook** – not taken up much

# Could self-management improve course of severe mental health problems?

- Our study adds to an already significant evidence base
- Currently sporadically implemented (WRAP, IMROC)
- Potential to be implemented throughout day-to-day care and beyond discharge
- Peers – particularly well-placed to deliver, combination of peer & self-management impressive in reducing relapse in our study
- But if part of long-term care, clinicians need to support too.
- **Challenge now:** find ways of weaving into fabric of mental health care
- Combine with other simple evidence-based interventions with potential to improve care for many – **shared decision making, carer psycho-ed, advance decisions.**
- **NB Advance plans the only intervention with supporting evidence in preventing compulsory admission**

## C. Social interventions as a potential tool to improve outcomes & lives

Well established relationship (probably bidirectional) between mental illness and social adversity, but:

- Guidelines – many drug & psychological interventions recommended, but:
  - NICE on depression: “consider befriending for chronic depression”
  - NICE on psychosis: supported employment, possibly peer support

### NICE guidance

Evidence-based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders.

# Why is social the poor relation in the biopsychosocial intervention triad?

- **Social targets are at multiple levels & in many sectors** – at societal, community, family, individual levels, sectors including health, social care, education, workplace etc.
- **Social care research** – relatively slow to develop
- **Fundamental change may require political action:** are we distracting from need for this with initiatives to reduce downstream impacts of poverty & inequality?
- **Is involvement of professionals/health researchers in areas like friendship & sexual relationships too paternalistic? Are we at risk of medicalising everyday life?**
- **Should we be standardising social interventions?** Many already delivered in various social care/charity sectors

# The case for researching social interventions in mental health

- Outcomes of mental illness not much improved through several decades of neuroscience/psychological research: a fresh opportunity to improve prognosis through focus on the social
- Service user priorities for research: tend to emphasise reducing burden of stigma, social exclusion, social adversity
- Considerable investment in untested models (e.g. social prescribing) – intuitively appealing models don't always work
- There are benefits to getting in the guidelines– e.g. shift away from social in EIP guidance in absence of evidence
- Call for more prevention in mental health – large proportion of potential targets are social

## Targets for social interventions in mental health - examples

	National	Community	Small group/family	Individual
General population	Anti-austerity measures	Improvements to built environment	Workplace wellbeing interventions	Mental health campaign promoting self-help
High risk populations e.g. perinatal, older people	Initiatives to alleviate poverty among older people	Centres promoting social life for new mums	Bringing young people into care homes	Apps to allow new mums to find company
People with common mental health problems		Access to leisure centres for people with depression	Education about loneliness for GP practices	Social prescribing in primary care
Secondary care service users			Peer support groups in day services	Supported employment

# Social interventions for people with severe mental health problems: evidence so far

Substantial supporting evidence	Preliminary evidence	Minimal evidence
Supported employment (in psychosis)	Interventions to increase social network size	Loneliness interventions
	Peer support to improve mental health outcomes (more for depression)	Support in sexual relationships
	Sexual health interventions	Support with financial problems & debt
		Support in successful parenting

# Loneliness: an example of a social target for intervention development in mental health

Farhana Mann and Sonia Johnson: Addressing loneliness will take more than appointing a minister

February 13, 2018

*Enthusiasm must be matched by evidence and one size will not fit all*



The recent appointment of the UK's first minister for loneliness was met by many with excitement and hope. Some, however, have questioned whether it can really bring about change in an aspect of people's life, such as friendship and family relationships, which can be very private. And are these private domains really the business of the government, professionals, and academics?

As psychiatrists—and researchers—interested in the impact of loneliness on our wellbeing, this is an important moment. There is cause for celebration: the [Jo Cox Commission on Loneliness](#) (whose recommendations included the appointment of such a minister) has worked tirelessly alongside other organisations to raise the profile of what is now seen as a major public health issue. However, tackling loneliness effectively will be a complex and challenging task.

Loneliness is defined as a mismatch between the level of social connectedness that a person desires and what they have. It is, by definition, an unpleasant experience—we are not referring to voluntary decisions to spend time alone or peaceful solitude. Loneliness is also a distinct concept from objectively “being alone.” It is entirely possible to feel lonely despite being surrounded by people. Definitions matter, because loneliness and objective isolation are partially independent risk factors for multiple poor health outcomes, and when people spend more time in company, they don't necessarily stop being lonely. Loneliness is associated with early mortality, cardiovascular disease, dementia, longer hospital stays, depression, anxiety, suicide, and other poor outcomes. It also has major social and economic costs. Needless to say, understanding and addressing loneliness will take more than appointing a minister.



**SOCIAL ISOLATION IN  
MENTAL HEALTH:**

A CONCEPTUAL AND METHODOLOGICAL REVIEW



## What is loneliness?

- Subjective, unpleasant state
- Not solitude
- Mismatch between what you have and what you want
- Related to (but distinct from) social networks, social isolation, social capital, living alone, marital status and other concepts
- Transient loneliness is normal – chronic loneliness probably more problematic

## Can you measure that?

- Complex, personal experience: fair to reduce to checklist?
- Validated measures: UCLA loneliness scale, DeJong Gerveld
- Widely used, reasonable psychometrics
- But not necessarily a close fit to personal experience

## ‘Risk factors’

- Older & younger people
- Lower income
- Carers
- Living alone/being unmarried/bereavement
- Physical disability, sensory deficits
- Mental health problems
- New mothers, students
- Refugees, ethnic minority groups
- Both men and women affected
- Substantial overlap with risk for mental health problems



## Mounting evidence on loneliness impact:

- Numerous physical and psychological impacts
- Greater morbidity/poorer outcomes for range of physical conditions e.g. stroke/cardiovascular disease
- Meta-analysis of 148 international studies: significantly increased risk of premature death
- Greater health service use
- Evidence for altered immune system function (eg HPA axis, natural killer cell activity, reduced inflammation)

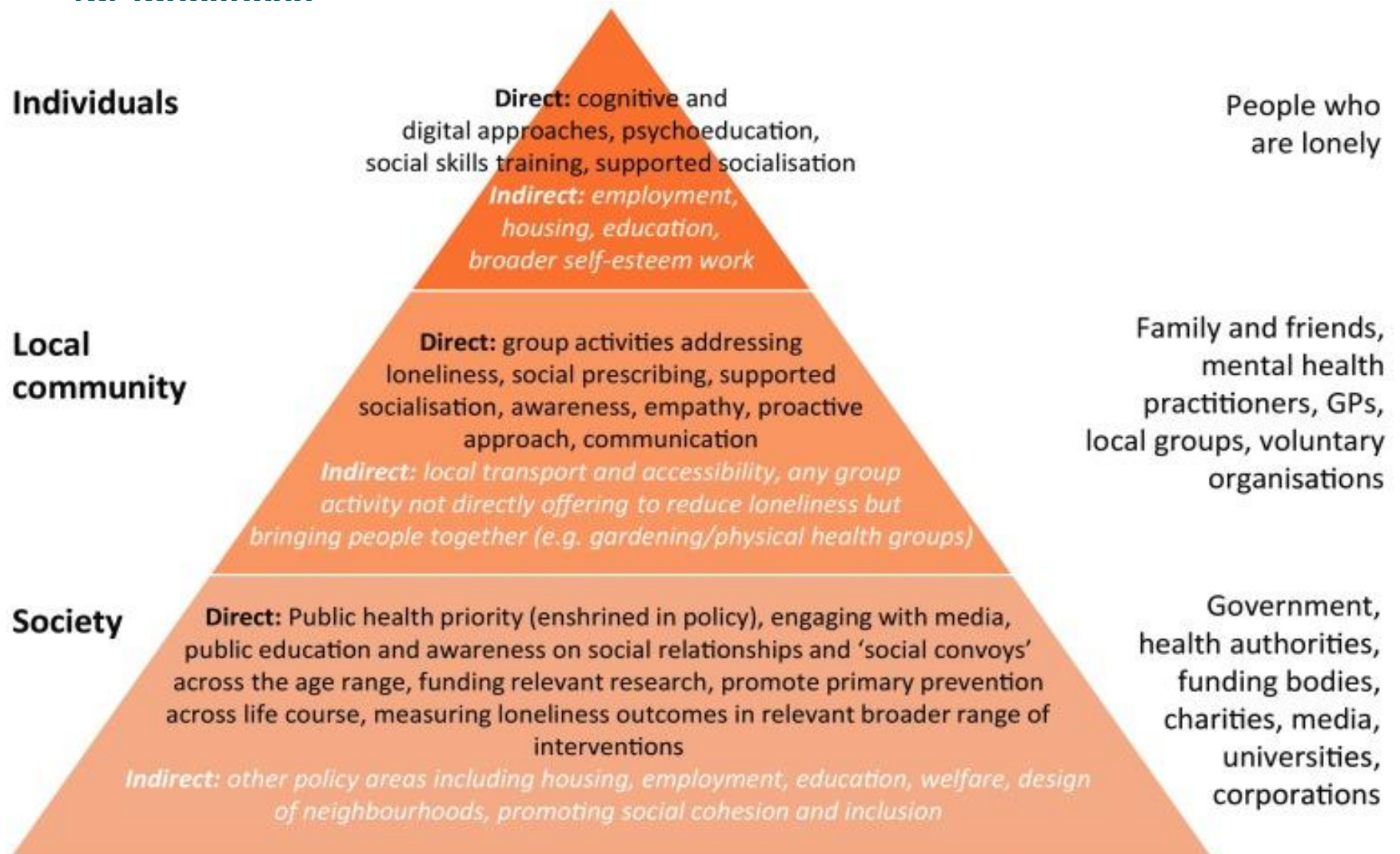
# Associations with mental health problems

Clear cross-sectional associations between being lonely and:

- Depression
- Anxiety
- Suicide and self harm
- Eating disorders
- “Personality disorder” diagnosis
- Psychosis

**Not so much longitudinal evidence – but lonely people more likely to become depressed, outcomes of depression worse for lonely people**

## Farhana Mann et al. – Potential levels and types of loneliness intervention for loneliness



# Addressing loneliness among mental health service users

- Currently no established and evidence-based strategies around to reduce loneliness among service users.
- Bidirectional relationship between mental health problems and loneliness complicates development of theory and interventions
- **Social vs. emotional loneliness**
- May need to adapt strategies that work in other populations.
- **Stigma and self-stigma** big issues, **social anxiety** also prevalent.
- Better understanding needed of how people experience loneliness, what help they would like – maybe corresponding measures
- Aspiration: to improve mental health outcomes by reducing loneliness
- But reducing loneliness may be a justifiable goal in itself
- **Community Navigator Study** – an example of research evaluation of an NHS-based anti-loneliness strategy

Study protocol | [Open Access](#) | [Open Peer Review](#)

# The Community Navigator Study: a feasibility randomised controlled trial of an intervention to increase community connections and reduce loneliness for people with complex anxiety or depression

Brynmor Lloyd-Evans  , Jessica K. Bone, Vanessa Pinfold, Glyn Lewis, Jo Billings, Johanna Frerichs, Kate Fullarton, Rebecca Jones and Sonia Johnson

*Trials* 2017 **18**:493

<https://doi.org/10.1186/s13063-017-2226-7> | © The Author(s). 2017

**Received:** 3 August 2017 | **Accepted:** 3 October 2017 | **Published:** 23 October 2017

 [Open Peer Review reports](#)



# **The Community Navigator Study: a feasibility study of an intervention to reduce loneliness**

- 8 meetings of a study stakeholder working group (experts with lived experience, clinicians, researchers) to support co-production (with McPin Foundation)
- Inputs to co-production: consultation with experts in the field, including voluntary sector providers of community navigator and social prescribing services (especially Wellbeing Enterprises – Runcorn), relevant literature
- Intervention manual and theory of change model developed

# The Community Navigator Programme

## Structure

- Up to 10 sessions
- Up to 6 months
- £100 budget
- Additional group element
- Adding to standard care
- Training from study team/CDAT practitioners
- Supervision from MH service social workers

## Key components

- Mapping my social world
- My connections plan
- Social identity building
- Solution-focused approach
- Help only with social contact/connections

# Community navigation - example

CI1: Now – Meditation classes, Health Condition Group, Film  
Previously – Sport and outdoors, volunteering, music

	Miss	Maybe	Hit
Volunteering	KCL	City Farm Neighbourhood Centre	
Film	Local film club		Neighbourhood Centre film group
Sport		Local football team Cricket club trips	
Outdoors		City Farm	TH Walking Group ( <b>new friend</b> )
Social	Adult Ed	Recovery College Family plans	Neighbourhood Centre (lunch club, film group > weekend trip with <b>new friends</b> )

Reported impacts:

- More active, more confident
- More comfortable with others even if no point of connection (health condition)
- Finding interpersonal contact easier (e.g. brother-in-law)

# Feasibility trial combined with qualitative evaluation

- In four London Boroughs, 2015-2018
- 30 experimental vs. 10 controls randomised to Community Navigator vs. directory of local resources

## Findings:

- Straightforward recruitment
- High acceptability & good retention
- Popular with staff and service users
- Hard to take small steps forward in a very anxious population – longer might have been beneficial
- Not powered to detect significant effect

## Some challenges for researching loneliness interventions

- RCT evidence more problematic than for less complex interventions:
  - Social context at various levels a major influence on how well a model works (e.g. the job market, social assets of community)
  - Community-level interventions are hard to research through RCTs
- Intervention strategies need to be individualised:
  - Changing cognitions vs. helping connect
  - Tailored to interests (music/sport/spirituality....)
  - Reconnecting vs. making new links
  - Peer support vs. back into wider world
  - NHS vs. other sectors
  - Digital vs. IRL

But –

- Mental health service users/survivors often supportive
- Many potential cross-disciplinary collaborations
- Potentially great untapped potential for benefiting quality of life and outcomes



## Mental Health and Loneliness Network

@UCL\_Loneliness

Tweeting about research on loneliness/social isolation & mental health and the work of the new @UKRI\_news-funded cross disciplinary network on this theme

📍 UCL Division of Psychiatry

Tweets	Following	Followers	Likes	Lists	Moments
788	243	857	103	2	0

Tweets   Tweets & replies   Media

📌 Pinned Tweet



**Mental Health and Loneliness Network** @UCL\_Loneliness · Sep 8

1. Here is a thread to explain Loneliness and Social Isolation in Mental Health #MHLoneliness network, one of 8 new #MentalHealthNetworks funded by the @UKRI\_News. It will be jointly led by @soniajohnson & @DrAPitman both @UCLPsychiatry . [ukri.org/news/uk-resear...](https://ukri.org/news/uk-resear...)

💬 2   ↻ 33   ❤️ 40   📌

Show this thread

# UKRI Network on Loneliness and Social Isolation in Mental Health

- Interdisciplinary network to develop collaborations, fund small projects, seed larger ones – from 1 Dec 2018 (leads S.Johnson & A. Pitman)
- Questions:
  - Can we prevent mental health problems through interventions targeting loneliness/isolation?
  - Can we reduce loneliness in people with mental health problems (and so improve outcomes)?
- Disciplines include psychology, social psychiatry, epidemiology, sociology, music, art, architecture, digital technology, sports science....
- Major role for Lived Experience Working Group
- Scoping, establishing research priorities, funding small projects, seeding bigger applications

## In summary

- Let's not just wait for great leaps forward in pharmacology/psychology to improve lives of people with severe mental health problems via research
- **A proposal for new research priorities** for the next decade:
- Aim to enrich mental health care throughout NHS through more focus on simple strategies that a variety of people can support:
  - Rigorous research-supported implementation of well-developed models with clear evidence e.g. IPS, family intervention, high fidelity crisis care & early intervention in psychosis
  - Refinement & testing (implementation-evaluation studies) of straightforward evidence-supported interventions e.g. self-management, advance plans, shared decision making
  - Developing & testing innovative social interventions e.g. in loneliness
- **Rigorous and creative cross-disciplinary and cross-sector research with lived experience at centre needed to underpin all of these**



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The views expressed are those of the author and not necessarily those of the NHS, the NIHR or the Department of Health.

<https://www.ucl.ac.uk/core-study>

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<https://www.ucl.ac.uk/psychiatry/research/epidemiology/community-navigator-study>

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