McPin Foundation
Transforming mental health research

Working on research to address loneliness and build *social* connectedness: reflections from three studies

Vanessa Pinfold, Co-founder and Research Director

RNN, 7th November 2018 Berrylands Hospital Northampton

About us

- Mental health research charity
- Champion **expertise** from experience
- We have a lot of studies using **peer research methods**
- We are interested in **developing methods** for PPI (patient and public involvement) and peer research including use of disclosure
- We have done various projects looking at peer roles – much more to do!

Acknowledgements

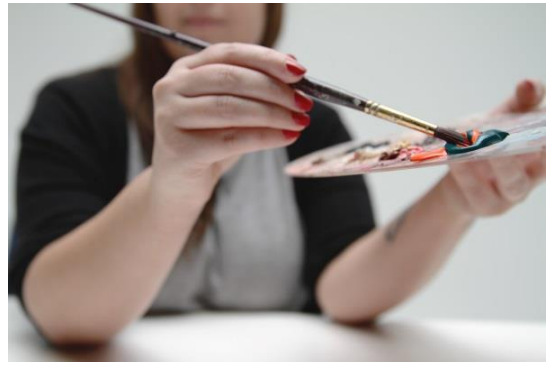
- **Community Navigators study** – working with people with complex depression and anxiety to address loneliness
  - *Lead Dr Brynmour Evans and Professor Sonia Johnston, UCL. NIHR SSCR funding*.
- **Hounslow Wellbeing Network** – building on research on wellbeing networks funded by NIHR HS&DR
- **Wellbeing mapping project** – managing transition between secondary and primary care
  - *Lead Dr Claire Henderson (KCL) with Dr Steve Gillard (UoL, St George's). South London CLAHRC funding*.
- **Connecting People study** – implementation research
  - *Lead Professor Martin Webber, University of York. NIHR SSCR funding*.

Commonality

The research we are involved in has tended to ...

- Develop new worker roles or new emphasis within existing roles encouraged

- Involved peers in research process



- Create a lens for looking at the “social” which is broader than most, extending beyond social relationships

Current …

Campaign to EndLoneliness

CONNECTIONS IN OLDER AGE

Soc Psychiatry Psychiatr Epidemiol
DOI 10.1007/s00127-017-1392-y

INVITED REVIEWS

A life less lonely: the state of the art in interventions to reduce loneliness in people with mental health problems

Farhana Mann[1] · Jessica K. Bone[1] · Brynmor Lloyd-Evans[1] · Johanna Frerichs[2] · Vanessa Pinfold[2] · Ruimin Ma[1] · Jingyi Wang[1] · Sonia Johnson[3]

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Long standing

”No Man Is an Island” by John Donne

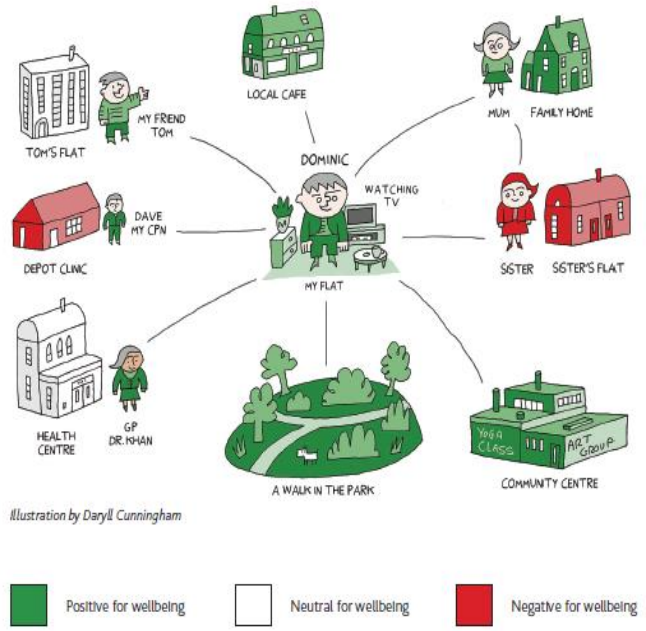
No man is an island, entire of itself;
every man is a piece of the continent,
a part of the main.

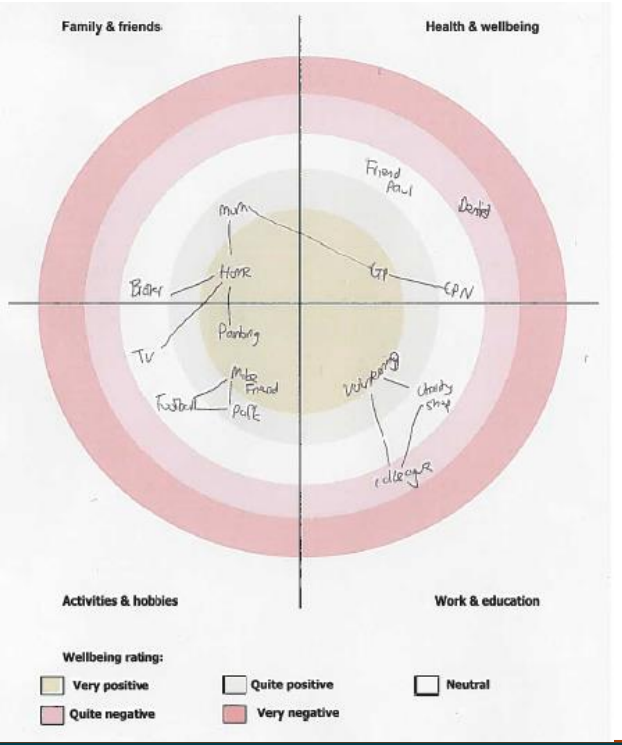
In this poem, John Donne explores the idea of the connectedness of people. People are not isolated islands. We are all a part of a larger thing, and if one person dies, everyone is affected.

Reference:https://www.mensaforkids.org/MFK2/assets/File/Read/MFK-Poetry-1.pdf

Personal interest – wellbeing mapping

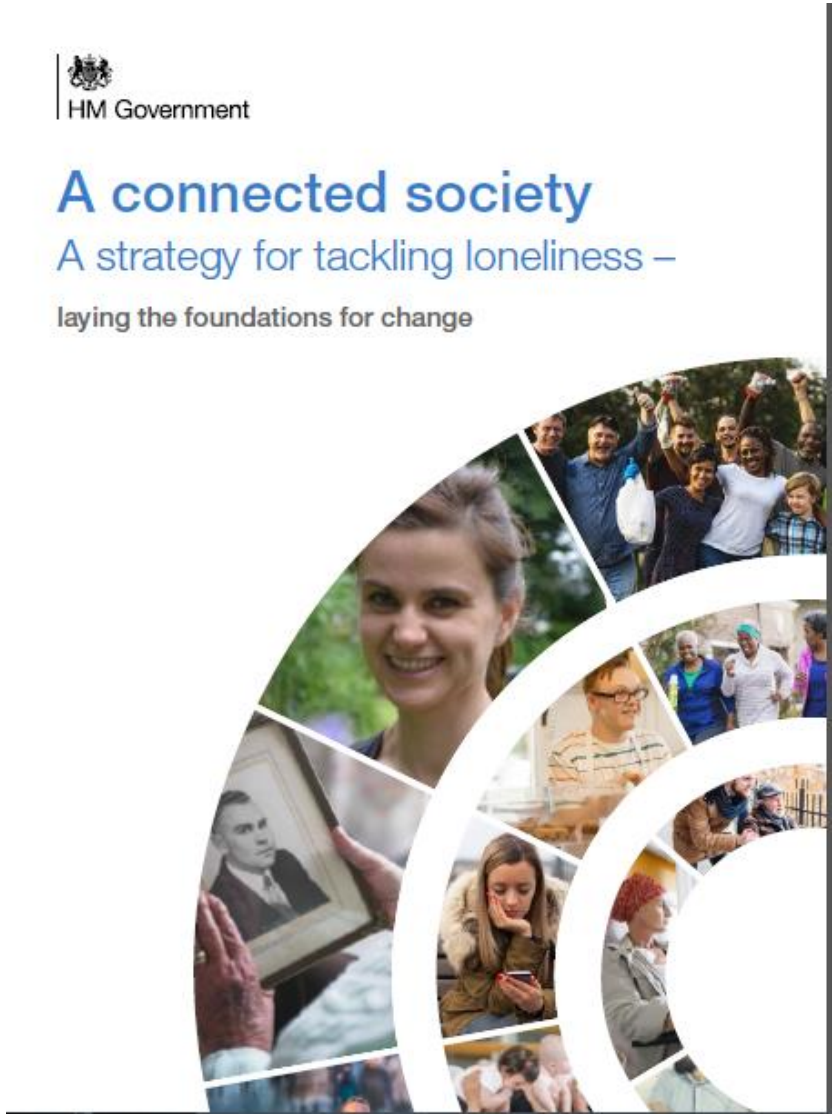
- Offer other ways to engage people – same ideas, different presentation.





Focus today …

- Challenges for health research and researchers
- Promising signs
- Where next?



Challenge 1: definitions

Introduction

Loneliness refers to a subjective unpleasant feeling arising from a mismatch between a person's desired level of meaningful social relationships, and what they perceive they actually have [1]. It is related to (but distinct from) a range of concepts, such as social isolation, social capital, and social network, which are measured using objective means (Table 1). Crucially, it is the persistent subjective feeling of loneliness that has been shown to be a strong independent indicator of multiple physiological changes and poor health outcomes [2–8].

Talking about loneliness

I couldn't be around people so I became isolated and lonely really.

How would you describe isolation and loneliness?

It is horrendous. It's soul destroying. [became tearful]

Sorry. Shall I just

No, it's alright. It's okay.

Sorry.

No. It is, it's soul destroying. You still have who you are inside you, like the xxx and so on but you can't access it anymore. Instead of waking up and saying, "I'll have a day to myself today where I can get on with my work," instead you just have anxiety, depression, feeling like you're never going to leave the flat again, that you're cut off forever, all doom and gloom stuff comes over you.

Social connectedness, is it different?

- “The emphasis on social connectedness is on the independent self in relation to others. Social connectedness, in this sense, is different than belongingness as defined by group membership or peer affiliation and loneliness as defined by emotional feelings regarding the loss of specific relationships” (Lee et al 2001)
- “Connectedness denotes the construction and successful maintenance of reciprocal interpersonal relationships” (Ware et al 2007)

Challenge 2: measurement

- What is the best way to capture connectedness or loneliness?
- Do we need new scales across the life course – young people's to older people's experiences vary?
- De Jong (6-item)

In this 6-item scale, 3 statements are made about 'emotional loneliness' and 3 about 'social loneliness'. (Social loneliness (SL) occurs when someone is missing a wider social network and emotional loneliness (EL) is caused when you miss an "intimate relationship".[18])

1. I experience a general sense of emptiness [EL]
2. I miss having people around me [EL]
3. I often feel rejected [EL]
4. There are plenty of people I can rely on when I have problems [SL]
5. There are many people I can trust completely [SL]
6. There are enough people I feel close to [SL]

The scale generally uses three response categories: **Yes / More or less / No**

UCLA – 3 item

This scale comprises 3 questions that measure three dimensions of loneliness: relational connectedness, social connectedness and self-perceived isolation. The questions are:

1. How often do you feel that you lack companionship?
2. How often do you feel left out?
3. How often do you feel isolated from others?

The scale generally uses three response categories: **Hardly ever / Some of the time / Often**

Challenge 2: measurement

- Social network mapping

Raj from London: Formal and sparse

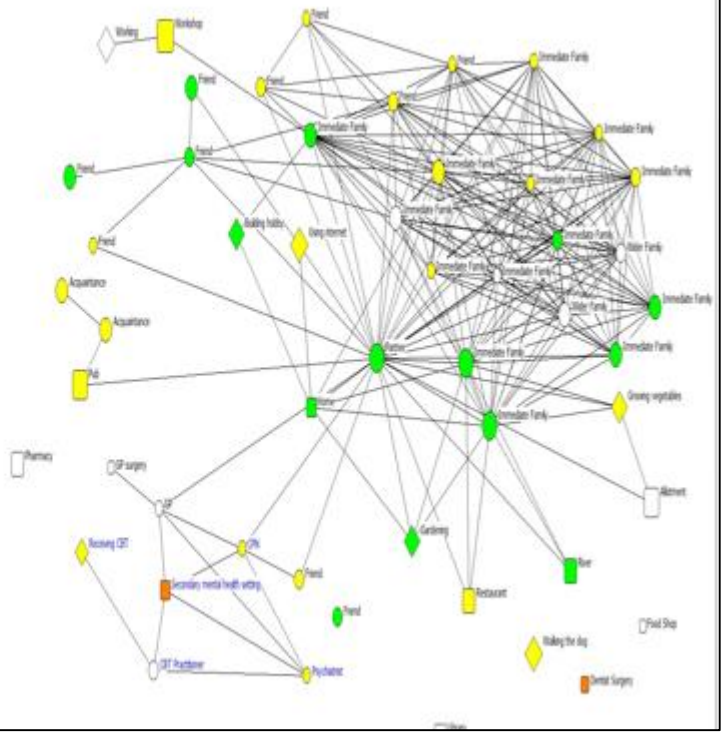
- Schizophrenia
- Asian and male
- Aged in his 40's
- Lives alone
- Unemployed
- 'reliable', 'safe',

with 'zero chaos'

Matt from the SW: Family and stable

- Bi-polar disorder
- Male, aged in 40's
- White British
- Lives with wife, 2 k
- Self-employed
- positive' and

'supportive', with 'stability'



Challenge 3: solutions

- Many are practical, common sense approaches but can be **difficult to implement** (and also research)
- We have found that implementation requires good quality **supervision** – not always available
- Tendency to **under estimate skill level** required in “supporter” roles that deliver social connectedness interventions
- Important to recognise there are different ways of building **community connectedness**, sense of belonging, steps before / towards addressing loneliness and social connectedness.

Challenge 3: solutions

- We have observed where **peer roles** are involved the peers can benefit from the intervention as well as the ‘supported’.
- This might be because supervision is delivered in group settings, or/and workers are encouraged to ‘peer support’ each other
- **Length of intervention** seems to be a point of tension. Cost of implementation and risk of building dependency vs time to realistically support real sustained change in social connectedness

Promising signs: Wellbeing mapping

Goal was improvements in physical health through better engagement with primary care, social network changes a secondary priority:

- People found the 6 sessions “helpful”
- Some enjoyed visualisation element, others less so
- Most importantly, conversations helped people identify who was in their network and how they might be approached for support – who was helpful or less helpful
- The beginning of small changes in behaviour were spoken about

Promising signs: Connecting People

A programme being implemented in secondary mental health teams, already shown to enhance social capital, but can it be implemented into routine care?

- Too early to say anything about results but has been very hard to recruit teams and participants into the study
- Positive feedback about resources that have been produced with the coproduction working group

Promising signs: Community Navigator study

Feasibility and acceptability trial among people with complex depression and anxiety to address loneliness

- It was feasible to deliver the project and we hope to apply for full RCT in 2019 to build evidence base
  - We might be addressing more intermediate outcomes than primary
  - We believe there are benefits of linking to clinical services but is the model sustainable?
- It was acceptable and we are writing up findings!
  - Focus on individual differences and paying attention to narrative voice

Reflection round up

This work is and feels important and coproducing the solutions has been best for us thus far.

Root this work in a public health discourse. The ordinariness of building social connections and addressing loneliness is something everyone understands.

The steps leading to the ‘social’ goal, are important. People, **places and activities** are all relevant. Meaningful connections are not only about social relationships.

Thank you!

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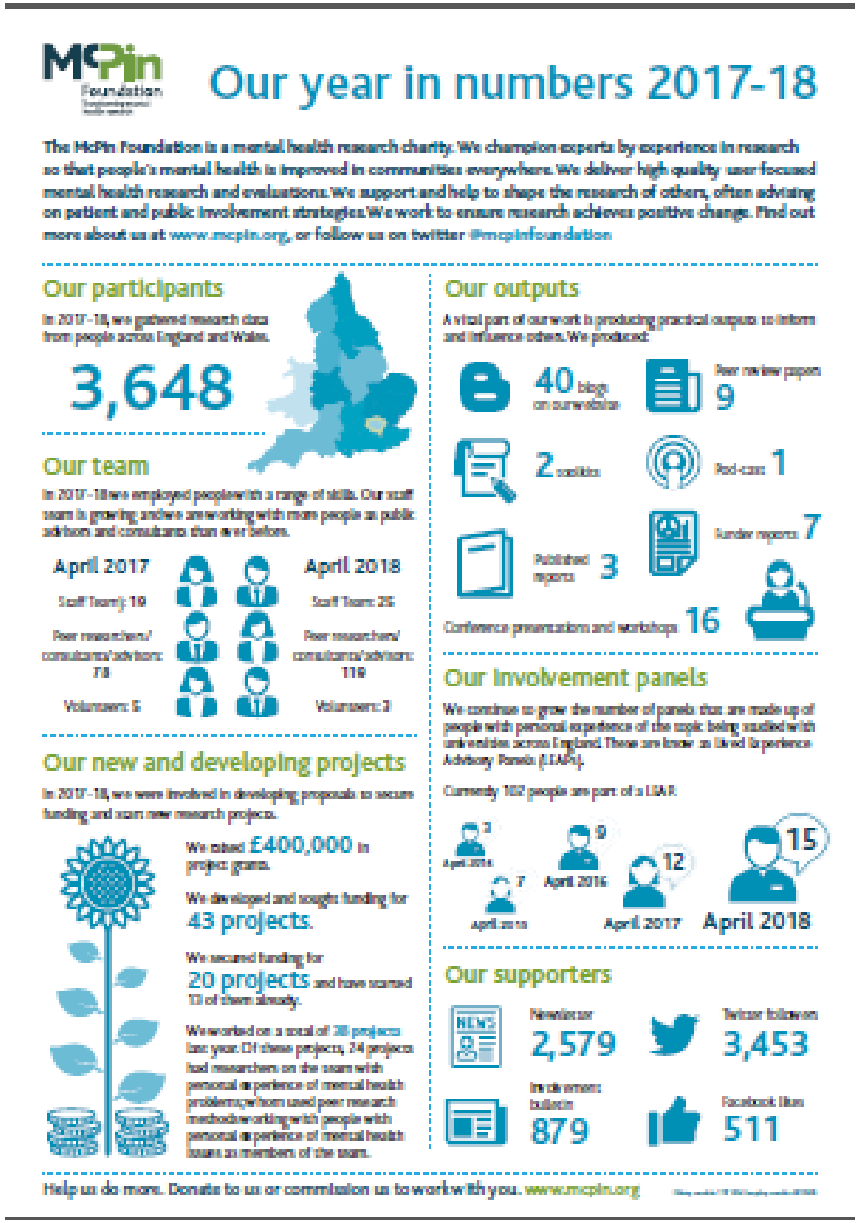

McPin Foundation

Our year in numbers 2017-18

The McPin Foundation is a mental health research charity. We champion experts by experience in research so that people's mental health is improved in communities everywhere. We deliver high quality user focused mental health research and evaluations. We support and help to shape the research of others, often advising on patient and public involvement strategies. We work to ensure research achieves positive change. Find out more about us at www.mcpin.org, or follow us on twitter @mcpinFoundation

Our participants

In 2017–18, we gathered research data from people across England and Wales.

3,648

Our team

In 2017–18 we employed people with a range of skills. Our staff team is growing and we are working with more people as public advisors and consultants than ever before.

April 2017	April 2018
Staff Team: 19	Staff Team: 25
Peer researchers/ consultants/ advisors: 78	Peer researchers/ consultants/ advisors: 119
Volunteers: 5	Volunteers: 3

Our new and developing projects

In 2017–18, we were involved in developing proposals to secure funding and start new research projects.

We raised £400,000 in project grants.

We developed and sought funding for 43 projects.

We secured funding for 20 projects and have started 13 of them already.

We worked on a total of 30 projects last year. Of these projects, 24 projects had researchers on the team with personal experience of mental health problems, who then used peer research methods working with people with personal experience of mental health issues as members of the team.

Our outputs

A vital part of our work is producing practical outputs to inform and influence others. We produced:

40 blogs on our website
Peer review papers 9
2 toolkits
Pod-cast 1
Published reports 3
Funder reports 7
Conference presentations and workshops 16

Our involvement panels

We continue to grow the number of panels that are made up of people with personal experience of the topic being studied with universities across England. These are known as Lived Experience Advisory Panels (LEAPs).

Currently 102 people are part of a LEAP.

3 April 2016
7 April 2016
9 April 2016
12 April 2017
15 April 2018

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