Untapped Potential

How people with lived experience of mental health issues engage in civic and public life

A research study in Scotland, June 2018

VOX SCOTLAND
Voices of eXperience

Mental Health Foundation

NATIONAL LOTTERY FUNDED
BIG LOTTERY FUND

UNIVERSITY of STRATHCLYDE
INTERNATIONAL PUBLIC POLICY INSTITUTE
CENTRE FOR HEALTH POLICY

Lived Experience
Research Collective

Commissioned by

drill
Disability Research on Independent Living & Learning

Authors

G. Johnston

M. Syrett

B. McElwee

H. Tweedie

L. Curtice

N. Quinn

C. White

W. McAuslan

This report utilised co-production methodology, where members of the Lived Experience Research Collective (Gordon Johnston, Michel Syrett, Benjamin McElwee, Heidi Tweedie) developed, directed and delivered the project. Research advice and support came from Lisa Curtice and Neil Quinn at Strathclyde University, support and guidance were provided by Chris White at the Mental Health Foundation and the project was facilitated by Wendy McAuslan at VOX who oversaw the project management.

Public Life Matters – Final Report

“Untapped Potential”
June 2018

Contents

Appendices:

Public Life Matters is a research project funded by DRILL - the Disability Research on Independent Living & Learning programme. DRILL is fully funded by the Big Lottery Fund and is delivered in partnership by Disability Action, Disability Rights UK, Disability Wales and Inclusion Scotland.

This report outlines the results of a participative research project funded under the first round of DRILL grants in Scotland and carried out during 2017/18. The grant was awarded under the theme of ‘participating in civic and public life’.

Public Life Matters is a partnership project. It was conceived by individuals from several organisations and developed and delivered in a collaborative manner. The grant holder is VOX (Voices of Experience), Scotland’s national collective advocacy organisation for people with lived experience of mental health conditions. VOX had overall responsibility for financial and project management.

The research was carried out by peer researchers from the Lived Experience Research Collective, a consortium of applied researchers, all of whom have lived experience of mental health conditions.

The Collective was formed in 2015 by See Me and IRISS and has been hosted by the Mental Health Foundation in Scotland since January 2016. It bids for research projects that require or benefit from the active involvement of people with lived experience, acts as a think tank for the Foundation on emerging issues and topics that might form the basis for future research projects and validates and comments on the Foundation’s ongoing research activities. The Collective champions and promotes co-production, inclusivity, collaboration and consensus in the way it works with the Foundation and with other research partners.

Expert advice on research methodology, design and ethics issues was provided by the Mental Health Foundation Scotland and the Centre for Health Policy at the University of Strathclyde. Ethical approval for the project was awarded by the Ethics Committee of the University of Strathclyde.

The project aimed to investigate four research questions:

- What proportion of people with lived experience of mental illness would like to increase their engagement with civic and public life?
- What civic/public roles do they aspire to?
- What barriers prevent them from playing a more active role in civic and public life and what are the potential solutions to overcome them?
- What policy initiatives could be put in place to overcome these barriers?

This report details the research carried out, provides analysis of the results and makes recommendations that we feel are required to enable the involvement of people with lived experience of mental health conditions in civic and public life.

Executive Summary

1

Policy Context and Literature Review

Legislation and policy within Scotland creates a firm footing to build community empowerment, recognising the importance of community connectedness, cohesion, autonomy and participation in improving public mental health.

We therefore have a sound basis on which to consider whether people with lived experience of mental health conditions would like to increase engagement with their communities and what barriers may prevent them from playing a more active role.

An extensive review of the literature on community engagement, human rights, recovery and citizenship within a mental health context shows the clear value of increased engagement with communities for people with lived experience of mental health conditions.

We conclude that prerequisites for greater involvement include greater consideration and encouragement from public bodies and enabling involvement through the provision of appropriate social supports.

Our Methodology

We developed, tested and distributed a survey titled “Public Life Matters 2017”. This was publicised through social media and partner community-based mental health organisations. We received 249 completed responses by September 2017. An initial statistical analysis led us to identify key conclusions and areas of interest, which were discussed at our six focus groups held throughout Scotland in late 2017.

We then revisited our statistical findings alongside the feedback from the focus groups, bringing quantitative and qualitative data together to reach a series of conclusions. From there we developed our recommendations.

Our Survey

The key findings drawn from analysis of the 249 responses to our survey are:

- 50% of all respondents expressed a wish to increase their level of involvement in public life. We have therefore identified a massive untapped potential of people who wish to become involved, or more involved, in their communities.
- The strongest reasons for non-involvement were stress and/or anxiety (3.86 weighted average on a five point Likert scale) and lack of confidence (3.13).
- Stigma and discrimination was not identified as a major issue (2.67), although we suspected that this was a terminology issue and that some of the reported lack of confidence might well have come from fear of discrimination.
- When asked about potential barriers to greater involvement, stress and/or anxiety was most common (3.45) followed by lack of confidence (3.15).
- The most popular roles aspired to were volunteering (49%) and activist (41%). Becoming a trustee or director of a charity or community organisation (22%) and standing for election to public office (10%) were more attractive than might be expected.
- 76% of respondents used social media sites, such as Facebook or Twitter. Not surprisingly, the usage rate decreased with age, from 100% in under 25s to 52% in over 60s. Of social media users, 91% had used to it seek information on their community and 71% had participated in online campaigns.
- More information was the support required to increase involvement for 60% of respondents; 55% cited peer support, 50% training and 37% mentoring.
- Participation in each of five recent local and national elections was high amongst participants, with over 70% reporting having voted in all cases.
- When asked to summarise the barriers to participation in their communities in a free text question, thematic analysis showed the most common responses to be self-confidence (28%), the impact of a mental health condition (22%) and lack of time or other commitments (16%).

Our Focus Groups

The most important findings taken from our analysis of discussions at our six focus groups held across Scotland were:

- Being involved in the community was primarily defined as volunteering, and as a positive experience.
- Key barriers identified in discussions were self-stigma, stigma in the community (either experienced or anticipated) and a fear of a negative impact on social security entitlements.
- The best ways of overcoming barriers were a physical place to go for information and direct support from another person. Most did not distinguish between peer support and mentoring, simply looking instead for some assistance and support.
- Social media was seen as a positive means of participation by some, but many used it for social purposes only, while others had no interest in going online at all.
- All participants who had become involved in their communities would recommend that other people with lived experience get involved too.

Discussion

While we would not attempt to argue that the exact percentage figures we quote are necessarily representative of all people with lived experience of mental health conditions, we are very confident in our primary research finding:

- A large percentage of people with lived experience of mental health conditions would like to become involved, or to get more involved, in their communities. This represents a tremendous untapped potential for our civic and public life.
- The most common roles sought were volunteer and activist. We realise that many people use these terms in a relatively informal manner, talking of wanting to “help out” and primarily wishing to assist others.
- Discussions on barriers led us to conclude that results around both lack of confidence and stress/anxiety stemmed from a combination of self-stigma (e.g. questioning your own ability to contribute effectively or to maintain a commitment because of mental ill health) and anticipated stigma (e.g. a fear of being judged to have little to offer or being abused because of your mental health status).
- Discussion on support needed showed that many people do not know where to go for information on local activities. Online information is useful for some, but others prefer having a physical place to go to where they can speak directly to someone. Many require support to get involved, although do not look to formal peer support or mentoring but rather for someone to accompany and support them.
- We also saw evidence that a lot of community groups are not viewed as welcoming to potential new members and that many outside the mental health field were felt to hold attitudes that would be called stigmatising.

Our Recommendations

We have developed a series of recommendations aimed at tackling the barriers found to prevent people with lived experience of mental health conditions from playing a full part in the lives of their communities.

- The Scottish Government should ensure the Local Governance Review engages directly with people with lived experience of mental health conditions.
- The Scottish Government should audit Participation Requests by geography and community of interest or identity.
- Local Authorities should adhere to the National Standards for Community Engagement and evaluate the impact of engagement, whilst also regularly auditing the resource they invest and the extent to which it facilitates participation and civic engagement.
- Local Authorities should invest in staff capacity to enable increased community engagement, including that of seldom heard groups, and monitor diversity and impact.
- Local Authorities should ensure third sector and community groups are inclusive in relation to mental health.
- Healthcare Improvement Scotland’s iHub’s Practice Administrative Staff Collaborative should test models to up-skill practice staff.
- Health and Social Care Partnerships should

identify, through Primary Care Improvement Plans, opportunities for links workers within GP practices and volunteers to enable participation in communities, including 'proactive signposting', where they support people to attend appointments or community groups, etc.

- Health and Social Care Partnerships and Community Planning Partnerships should identify opportunities for Advice and Advocacy Workers to be based within Primary Care and Job Centre settings.
- Health and Social Care Partnerships should ensure they enable third sector, carer and service user representatives on Integrated Joint Boards to be adequately supported and must address previously raised concerns.
- Health and Social Care Partnerships should also ensure inclusive opportunities for public involvement, engagement and representation beyond Integrated Joint Board meetings.
- Mental health services should orient themselves towards a recovery focus, ensuring encouragement of, and support for, people with mental health issues to take up opportunities in volunteering, education and employment.
- Mental health service providers should actively promote the use of co-production in the development of services.
- Educational settings, including nurseries, primary and secondary schools, and further and higher education institutes, should acknowledge the important role of active citizenship in supporting mental wellbeing, as well as the barriers to achieving this for people with lived experience of mental health conditions, and consider how they can enable this.
- Public libraries should facilitate mental and physical wellbeing through up-skilling staff to help people to seek relevant information and advice. This is as identified by the 'Public libraries skills strategy 2017-2030, and Scotland's Health Literacy Action Plan 2017-2025, Making it Easier.
- All organisations engaging volunteers should offer those with lived experience of mental health conditions the same 'reasonable adjustments' as specified in the Equality Act 2010 that they offer to their paid employees.
- Organisations should provide peer support or buddying services (paid or voluntary) to facilitate the participation of people with lived experience of mental health conditions.
- Organisations should improve their own awareness of mental health conditions and consider whether their activities are operated in an inclusive manner that would eliminate stigma and discrimination against those with lived experience of mental health conditions.
- Political parties should advertise their willingness to consider applications as candidates for public office from people with lived experience of mental health conditions.
- Research funders should support studies conducted by researchers that focus on the links between citizenship and recovery.

Policy Context & Literature Review

2

Policy Context

The Commission on the Future Delivery of Public Services[1] (the Christie Commission) proposed a suite of recommendations for public service reform within Scotland. These primarily focused on prioritising prevention and tackling inequalities by designing services with and for people and communities, based upon their needs, talents and assets; embedding community participation in the design and delivery of services; maximising resource by better partnership working and integrating services. It also highlighted the need for greater transparency and accountability of public services, enabled by data and the measuring of outcomes.

That report has informed recent legislation such as the Public Bodies (Joint Working) Act 2014[2] (Health and Social Care Integration) and the Community Empowerment Act 2015[3]. Both pieces of legislation drive forward the public service reform agenda and aim to enable significant opportunities for citizens to engage in and inform service design, delivery and evaluation. Furthermore, the associated National Health and Wellbeing Outcomes (NHWOs) and National Performance Framework (NPF) include outcomes relevant to this research:

- People are able to look after and improve their own health and wellbeing and live in good health for longer (NHWO#1);
- Health and social care services contribute to reducing health inequalities (NHWO#5);
- We live in communities that are inclusive, resilient and safe (NPF);
- We respect, protect and fulfil human rights and to live free from discrimination (NPF); and
- We are healthy and active(NPF)

The Local Governance Review[4], likely to result in a Local Democracy Bill in 2019, is intended to build upon the ethos of both the Christie Commission and the Community Empowerment Act, as well as the recommendations of the Commission on Strengthening Local Democracy[5], and further devolve power to communities, enhance participation in public service decision making, and drive inclusive economic growth. Scotland is also part of the Open Government Partnership, as a subnational pioneer[6], which aims to make government work better for people through transparency, participation and accountability.

Similarly, the Scottish Government is currently refining ‘A Connected Scotland’, otherwise known as the Social Isolation and Loneliness Strategy, after a period of engagement and consultation. The draft strategy speaks of enabling communities to take the lead, building cohesive communities and investing resources to facilitate this. Indeed, the government has recommended that the issues of social isolation and loneliness are addressed by Health and Social Care Partnerships across Scotland and that links worker systems are included in any national strategy development, with a commitment to introducing 250 links workers by 2021, prioritising areas of deprivation. The new GP contract in Scotland[7] identifies the key role of GPs, GP Clusters and Primary Care in general in improving wellbeing, health and reducing inequalities by working collaboratively with community multi-disciplinary teams and third sector partners.

Scotland’s National Action Plan for Human Rights (SNAP)[8] recognises that the realisation of human rights for all must include full participation in society.

Participation is the first of the PANEL principles used in a human rights based approach: Everyone has the right to meaningful participation in decisions which affect them. These principles align closely with those on which Public Service Reform is already being pursued in Scotland.

As can be seen, legislation and policy within Scotland creates a firm footing upon which to build community empowerment, recognising the importance of community connectedness, cohesion, autonomy and participation, in improving public mental health. However, our collective

---

[1] http://www.gov.scot/resource/doc/352649/0118638.pdf
[2] http://www.legislation.gov.uk/asp/2014/9/contents/enacted
[3] http://www.legislation.gov.uk/asp/2015/6/contents/enacted
[4] https://beta.gov.scot/policies/improving-public-services/local-governance-review/
[5] http://www.localdemocracy.info/wp-content/uploads/2014/08/Final-Report-August-2014.pdf
[6] https://www.opengovernment.org.uk/scotlands-2017-subnational-action-plan/
[7] http://www.gov.scot/Resource/0052/00527530.pdf
[8] http://www.snaprights.info/wp-content/uploads/2016/01/SNAPpdfWeb.pdf

experiences have identified an implementation gap between supportive and empowering legislation and what this actually means for communities in practice.

It is with this in mind that we attempt to understand what being involved in the community means for people with lived experience of mental health conditions, how involved they are and aspire to be, what gets in the way, and what support might be needed to increase their levels of involvement.

Definitions

Citizenship is the measure of the strength of a person's connections to 5 R's: Rights, responsibilities, roles, resources, and relationships that society offers its members and their sense of belonging as validated by others[9]. In this way, it is a fluid concept, affected by changes in societal attitudes, personal empowerment, social capital, community cohesiveness and other factors.

Recovery is often referred to as a process, a conceptual framework, or a worldview[10]. It proposes that people with mental illnesses can recover personally– in that they are able to live fulfilled lives full of purpose and wellbeing – whilst still experiencing clinical symptoms. Conversely, it has been argued that it is possible to have low levels of subjective wellbeing in the absence of mental health problems[11].

Social Capital is a concept that enables explorations of the range of individual and community assets available to us that impact on our wellbeing, trust, sense of belonging and of individual and community empowerment[12]. Social networks and connections are core components of social capital.

Social Inclusion is the extent to which individuals and communities are afforded opportunities to be part of a diverse and flourishing society[13], have access to institutions and resources in the decision-making environment[14], and live lives free from stigma and discrimination. In identifying the importance of social inclusion in enabling wellbeing, 'inclusion health' has been described as an approach for "addressing the causes of the causes", and it has been argued that "social exclusion is deprivation upon stilts" due to the comparative impact social exclusion has on mortality rates[15].

Literature Review

Recovery in mental health has two different, but not mutually exclusive, components:

- Clinical recovery, rooted within the medical model and exemplified by the absence or temporary remission of clinical symptoms; and
- Personal recovery – the capacity to live a meaningful life and to participate as active citizens[16].

A systematic review has identified five key recovery processes: connectedness, hope and optimism, identity, meaning and purpose, and empowerment (the CHIME framework)[17].

The concept of citizenship in mental health has been defined as the strength of people's connections to 5 Rs – rights, responsibilities, roles, resources, and relationships.[18] [19] It also encompasses their sense of belonging and the extent of their social inclusion as participating members in a society – as validated by other citizens[20]. Therefore, citizenship marks the boundary between inclusion and exclusion – as Atterbury and Rowe[21] outline, "it is not merely an individual subjective experience but a politically constructed role and privilege with rights and responsibilities".

---

[9] http://projectcitizenship.com/citizenship-mental-health/
[10] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4418239/
[11] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2866965
[12] http://www.gov.scot/Resource/0050/00504535.pdf
[13] http://www.un.org/esa/socdev/rwss/2016/chapter1.pdf
[14] http://lcerpa.org/public/papers/LCERPA_2009-09.pdf
[15] http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32848-9/fulltext
[16] https://academic.oup.com/bjsw/article/45/suppl_1/i45/2472191
[17] Leamy M, Bird V, Le Boutillier C et al. A conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. Br J Psychiatry 2011;199:445-52.
[18] Rowe M., Kloos B., Chinman M., Davidson L., Cross A. B. (2001). Homelessness, mental illness and citizenship. Soc. Policy Adm. 35 14–31. 10.1111/1467-9515.00217
[19] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5478800/#B33
[20] Rowe M. (2015). Citizenship and Mental Health. New York, NY: Oxford University Press.
[21] https://www.ncbi.nlm.nih.gov/pubmed/28631834

Research has found a causal association running from individual social capital to general and mental health - with social isolation being strongly associated with mental health[22]. Experiencing discrimination from friends and immediate family, and in finding or keeping a job, has been found to be associated with reduced access to social capital[23].

Research has also suggested that for people with severe mental illness, the highest mental wellbeing is held by those with diverse and active networks[24]. A significantly higher proportion of social resources were provided by colleagues in those with diverse and active networks, whilst social capital resources provided by practitioners were higher in those with formal and sparse networks. The contribution of peer experience has also been shown to be important in improving individual mental health.[25]

The Scottish Rural Mental Health Survey Research by the Scottish Rural Agricultural College[26] identified challenges in receiving appropriate mental health support such as distance from services, transport issues, and the lack of socialising with others with mental health issues (reported by over 85%) – although whether this is through personal choice or lack of facilities remains unclear.

The researchers argue that for those with mental ill health in rural Scotland, "community" is not always sufficient as a support network. Their survey suggests that on top of geographic isolation, there is also a lack of social cohesion and social support, as the majority (over two thirds) of respondents felt unable to be open about their mental health problems.

This issue is more than a rural one, however. Recent research by Time to Change found that two thirds of people in the UK feel they have no one to talk to when it comes to personal conversations on topics such as mental health, money, or relationships.

See Me previously found that 48% of people think that fear of losing their job would make someone unlikely to disclose their mental health condition[27]; and a literature review[28] found that people with mental health issues find it difficult to discuss their condition with others, often due to the stigma attached.

Findings from the Our Voice Citizens' Panel (2018) identified peoples'[29] willingness to talk to the following about their mental health at work:

- Manager (40% very willing or willing);
- Human Resources department (41% very willing or willing); and
- Colleague (42% very willing or willing).

The Scottish Rural Mental Health Survey also uncovered a strong need and desire to create ways for people to connect with each other as a preventative mechanism.

Respondents called for these to be low-level, non-clinical, informal and through trusted people and networks. Previous research found mental health services often reducing the opportunities of service users to participate as full citizens[30], with one example being a supported housing service doing little to encourage people to participate in work or education[31].

The New Economics Foundation Review, Co-production in mental health[32], identifies the strongest theme to emerge in the literature as relating to "a cluster of outcomes related to improved social networks and inclusion". This encompasses stronger social relationships, a reduced sense of stigma, and a greater sense of belonging. A longitudinal study looking at the impact of redundancy on workers, found that trust and social contact were associated with better

---

[22] https://www.cambridge.org/core/journals/health-economics-policy-and-law/article/social-capital-and-selfreported-general-and-mental-health-in-nine-former-soviet-union- countries/32695CF10422887D060DED57BED6E1D5
[23] https://www.cambridge.org/core/journals/epidemiology-and-psychiatric-sciences/article/discrimination-against-people-with-severe-mental-illness-and-their-access-to-social-capital-findings-from-the-viewpoint- survey/215D72520304AC46626F61E45A7A348E
[24] http://bjp.rcpsych.org/content/early/2017/09/26/bjp.bp.117.203950/full-text.pdf+html
[25] https://pdfs.semanticscholar.org/2b36/e20e8a28ff79c3c6a48ef44f5b5a24c9087e.pdf
[26] https://www.sruc.ac.uk/downloads/file/3332/national_rural_mental_health_survey_scotland_report_of_key_ findings
[27] See Me, 2015 You Gov poll
[28] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214424/rrep654.pdf
[29] https://www.ourvoice.scot/697/documents/1418)
[30] http://onlinelibrary.wiley.com/doi/10.1111/inm.12046/full
[31] https://link.springer.com/article/10.1007/s10597-014-9779-7
[32] http://b.3cdn.net/nefoundation/ca0975b7cd88125c3e_ywm6bp3l1.pdf

mental health[33]; whilst a UK study found trust to be an important buffer against psychological effects of the 2008 recession[34].

Other research has highlighted related issues of social cohesion and mental health – for example, the finding that first-generation migrants are at greater risk of experiencing depression than natives, and that this is mainly due to experienced barriers to socioeconomic integration and processes of discrimination[35]. This is likely to be broadly comparable to those with lived experience of mental health issues who have experienced other citizens doubting their trustworthiness, reliability, and responsibility. It has been suggested that the degree to which they are accepted is dependent on "how well they adopt their society's rules and norms and appear as"normal"[36].

Previous studies have also shown a link between social capital and depression[37]. Thus, there is evidence of a two-way relationship emerging whereby lack of societal integration adds to risk of mental health difficulties and these difficulties hinder integration and citizenship.

The employment rate for disabled people in 2015 was 45.6% compared to 79.4% for those not classified as Equality Act core disabled and/or work-limiting disabled (excluding those who did not state their health situation)[38]. Whilst there are measures in place to increase the number of disabled people in work, reviews have highlighted that schemes such as Access to Work are limited in their impact for those with mental health issues[39]. In 2015/16, 28.8% of 16 -18 year olds with mental health conditions were not in employment, education or training compared with 6.9% of non-disabled people[40].

Having a degree-level qualification can significantly improve employment outcomes. 60% of disabled graduates were in employment six months after graduating, compared to 65% non-disabled[41]. Indeed, the World Health Organisation has as (one of only a few) indicators of success for its Global Disability Action Plan: the number of graduates from educational institutions per 10 000 population – by level and field of education.

Disabled people with long-term depression and particularly those with mental illness or phobias are under-represented in employment. 45.5% of disabled people with health problems lasting or expected to last more than one year, who had depression and anxiety as their main health problem, were in employment. For those experiencing long-term mental illness or phobias as their primary, or most significant, health issue, the picture has remained largely unchanged in over a decade, with just over a quarter in employment in 2016[42], compared to just under in 2003[43]. This is a lower proportion than any other disability group[44].

A literature review carried out by the Department for Work and Pensions[45] identified many of the barriers to accessing social security that we will be exploring in the current study in a wider access context. These include:

- Lack of social confidence (due to stigma and lack of understanding among general public and service providers);
- Barriers due to inappropriate communication channels for their condition;
- Transport barriers related to their condition (anxieties about leaving their home, using public transport, attending appointments without a helper); and
- Digital illiteracy (lack of access, skills or confidence and fears with computers).

The Equality and Human Rights Commission's review, Being Disabled in Britain[46], highlighted the gap in reported difficulties in accessing services related to health, benefits, tax, culture, sport and

---

[33] http://journals.lww.com/joem/Abstract/2014/07000/A_Longitudinal_Study_of_the_Mental_Health_Impacts.6.aspx
[34] http://www.sciencedirect.com/science/article/pii/S0277953616300636
[35] http://www.tandfonline.com/doi/abs/10.1080/13557858.2014.883369
[36] http://onlinelibrary.wiley.com/doi/10.1111/inm.12046/full
[37] van der Gaag and Webber 2007; Webber 2005
[38] http://webarchive.nationalarchives.gov.uk/20160107070948tf_/http://www.ons.gov.uk/ons/publications/re-reference-tables.html
[39] Sayce, L. (2011), 'Getting in, staying in and getting on: Disability employment support fit for the future'. Department for Work and Pensions. [accessed: 30 September 2015]
[40] https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf
[41] https://www.gov.uk/government/consultations/fulfilling-potential-a-discussion-about-disabled-people-and-the-government
[42] https://www.tuc.org.uk/sites/default/files/Mental_Health_and_Employment.pdf
[43] http://www.nfao.org/Useful_Websites/MH_Social_Exclusion_report_summary.pdf
[44] http://www.nfao.org/Useful_Websites/MH_Social_Exclusion_report_summary.pdf
[45] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214424/rrep654.pdf
[46] https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf

leisure for disabled people: In 2012-14 this was 45.3% for disabled people compared with 31.7% for non-disabled people.

It also highlights that there are barriers to political participation for people with mental health issues, particularly for people with autism and learning disabilities. 83% of people with mental health issues are on the Electoral Register, compared to 85% non-disabled people. It concludes that disabled people are under-represented in political office and public appointments.

Even within mental health organisations, it has been suggested that lived experience often puts higher-level leadership out of reach[47] despite the finding that having people with lived experience at the head of the organisation allows all staff members to “have really open conversations” about organisational direction.

Research has shown the value of older people going online to reduce social isolation[48] and a systematic review of Internet use for active ageing showed enhanced interpersonal interaction at individual level, increased access to resources within the community, and empowered social inclusion at society level[49].

It has been suggested that fostering a greater sense of belonging among residents may promote positive mental health within communities, and older adults may benefit most[50]. Associations between neighbourhood cohesion and wellbeing are stronger for adults over 60 compared with those over.[51] Another study concluded that neighbourhood social capital is generally beneficial to individual mental health[52]

Intergenerational projects can also enhance social cohesion and have been shown to have positive benefits on the mental health of all involved. An article from the Personal Social Service Research Unit at the London School of Economics[53] showed that intergenerational projects can lead to better psychological outcomes, including reduced anxiety and an improved sense of self-worth.

Previous research has argued for policy makers and practitioners to provide safe, enriching opportunities for children and young people to enhance and utilise their social support networks[54]. With regards to young adults, Groups 4 Health provides promising evidence that mental health, wellbeing and social connectedness can be improved by targeting social disconnection and enhancing social identity[55].

Recent research has attempted to quantify the wellbeing impact of such interventions, with the Compassionate Frome project reducing costs by 21% and emergency admissions by 17% across a three year period, whilst comparable costs and admissions rose across Somerset[56].

Other studies have suggested that joining and maintaining groups may be a viable and cost-effective intervention for depression[57] [58], and thus facilitating social participation should be encouraged. Additionally, within neighbourhoods it has been found that the negative effect of deprivation on mental health can be mitigated by social cohesion[59].

Discussion

The World Health Organisation’s European Mental Health Action Plan 2013-2020 proposes a three-pronged approach:

- Improve the mental well-being of the population and reduce the burden of mental disorders, with a special focus on vulnerable groups, exposure to determinants and risk behaviours;
- Respect the rights of people with mental health problems and offer equitable opportunities to attain the highest quality of life, addressing stigma and discrimination; and

---

[47] http://www.tandfonline.com/doi/full/10.1080/01612840.2017.1280106
[48] https://www.ncbi.nlm.nih.gov/pubmed/25986724
[49] http://journals.sagepub.com/doi/abs/10.1177/0733464815595509
[50] http://www.sciencedirect.com/science/article/pii/S1353829214000641
[51] http://www.sciencedirect.com/science/article/pii/S0277953614001312
[52] https://link.springer.com/chapter/10.1007/978-94-007-2309-2_8
[53] http://eprints.lse.ac.uk/62083/1/the-effects-of-intergenerational-programmes-on-children-and-young-people.pdf
[54] https://bmcpsychology.biomedcentral.com/articles/10.1186/2050-7283-2-7
[55] http://www.sciencedirect.com/science/article/pii/S0165032715312180
[56] https://www.resurgence.org/magazine/article5039-compassionate-community-project.html
[57] http://www.sciencedirect.com/science/article/pii/S0277953613005194
[58] http://www.sciencedirect.com/science/article/pii/S0165032714000573
[59] https://www.cambridge.org/core/journals/psychological-medicine/article/effect-of-neighbourhood-deprivation-and-social-cohesion-on-mental-health-inequality-a-multilevel-population-based-longitudinal- study/718B4A56CABD263BAC6CC4779E934EE9

- Establish accessible, safe and effective services that meet people's mental, physical and social needs and the expectations of people with mental health problems and their families.

Involving people in the decisions that affect their lives, whether at an individual level (e.g. a care package), or a community level (e.g. the commissioning of services), is not only recommended due to the policy framework within Scotland that enables it, and the fact that it will lead to a more effective use of total resources, but also because it will enhance individual and community trust, social capital and inclusion, and thus is likely to generate improved health outcomes via the process also.

Similarly, WHO's Health in All Policies framework[60], proposes an approach to public policies across sectors that takes into account health implications, seeks synergies, and avoids harmful health impacts to improve population health and health equity.

Considering the impact that issues related to upbringing and early life experiences have, therefore, cross-connection to policies (not just clinical) is essential. For example, Scotland's new social security system must consider the impact of not only the output (e.g. social security; tax credits; etc.) but also of the process on people (a prime example would be "the rape clause" for child benefits[61]).

Another key example related to this research would be how the Scottish Social Security Agency that is in the process of being established, can enable – and not penalise – community participation, particularly given the financial benefits it will generate through, for example, reduced hospital admissions and reduced use of health and social care services.

Within health and social care, it is vital that staff are conscious of the impact their relationships, conversations and actions (beyond clinical interventions) have on how people view the therapeutic experience and how this impacts upon their outcomes. An example taken from our focus groups saw staff members informally referring inpatients of a psychiatric unit to a former inpatient with the knowledge to signpost to community assets, supports and groups upon patients leaving the unit. Not only is this indicative of their belief in the possibility of recovery, but also in their acknowledgement of the value of lived experience as an asset and recognition of a mutual partnership of experiences by profession and experience.

The UN Human Rights Council's Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health[62] highlights obligations under the International Covenant on Economic, Social and Cultural Rights. It calls for a shift in paradigm away from the medical model towards promotion and prevention, addressing adversity in childhood and adolescence, and mainstreaming mental health. Furthermore, it argues for a model that supports community-based treatment, psychosocial interventions, recovery and peer support approaches, with human rights embedded throughout.

Recovery can be enhanced by supported employment[63], wrap-around support that promotes independence and social connectedness[64] (in the form of income maximisation advice [65], social prescribing[66], promoting an increase in social networks[67], etc.) as well as clinical approaches such as shared decision making and peer support.[68]

Research with service users has found that willpower is a prerequisite to recovery and that moving to a new place or having to make new friends is "tantamount to recovery"[69]. One focus group participant reported deciding, "I was going to have to start making a life for myself".

---

[60] http://apps.who.int/iris/bitstream/10665/112636/1/9789241506908_eng.pdf?ua=1

[61] https://www.engender.org.uk/news/blog/-5-things-you-need-to-know-about-the-family-cap-and-rape-clause1/

[62] https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf?OpenElement

[63] Heffernan, J., and Pilkington, P. (2011) Supported employment for persons with mental illness: Systematic review of the effectiveness of individual placement and support in the UK. Journal of Mental Health, 20(4), 368-380.

[64] Drake., R.E., and Whitley, R. (2014) Recovery and Severe Mental Illness: Description and Analysis. The Canadian Journal of Psychiatry, 59(5) 235-242.

[65] Glasgow Centre for Population Health (2017). The Deep End Advice Worker Project: embedding an advice worker in general practice settings. Retrieved from: http://www.gcph.co.uk/assets/0000/6242/Deep_End_FINAL_WEB.pdf

[66] NHS Health Scotland (2017) Evaluation of the Glasgow 'Deep End' Links Worker Programme. Available from: http://www.healthscotland.com/documents/29438.aspx

[67] World Health Organisation (2014) Social Determinants of Mental Health. Retrieved from: http://apps.who.int/iris/bitstream/10665/112828/1/9789241506809_eng.pdf

[68] Drake., R.E., and Whitley, R. (2014) Recovery and Severe Mental Illness: Description and Analysis. The Canadian Journal of Psychiatry, 59(5) 235-242.

[69] (van der Gaag and Webber 2007; Webber 2005

In another study it was found that participants valued engaging with mainstream community assets and going ‘beyond drop-ins’[70]. Previous research has highlighted the desires of service users to get to a halfway point between the mental health system and social communities outwith it - the adult education system and voluntary organisations have been suggested as avenues for these half-way points due to their understanding and acceptance of different social groups. However, the study acknowledged the inherent difficulties in dealing with individuals with high levels of distress[71].

A participatory action research study in Bristol demonstrates the positive impact of mainstream community participation on mental health service users’ recovery as well as the need for inter-agency cooperation[72]. Similarly, a participatory action research study by Moray Wellbeing Hub showed the benefits of participation in their development project with, for example, 77% of participants reporting they felt better able to self-manage their wellbeing.[73]

It has been stated that “recovery is not about “getting better” or ceasing to need support – it is about “recovering a life”; the right to participate in all facets of civic and economic life as an equal citizen[74] [75]. A strengths-based model assists people with lived experience to identify, secure and sustain the environmental and personal resources required to enable them to live, work and play in a normally interdependent way in the community[76]. The UN Report on the Right to Health[77] suggests that “the global burden of obstacles may be heavier than any burden of “mental disorders””.

To put it another way, “social factors rather than medical interventions are the main determinants of recovery from mental health difficulties[78].” Ensuring public policies are health promoting and altering social norms so that the health of all members of society is a priority, will lead to the biggest impact in improving population mental health and reducing risk of mental illnesses[79].

From this we can identify a few parallel and equally important conclusions –

- **People with lived experience of mental health conditions should be included in decisions that affect their lives for the personal and societal benefits achieved by being engaged in the process, as well as being able to inform the result of the process, so that it is more person-centred and asset-based, thus maximising the use of resources and improving outcomes.**
- **Public bodies, public services, community assets, community groups, and the places where people participate, work and play must do more to provide people with lived experience of mental health conditions the reasonable adjustments, social structures, and environments required to remove “the global burden of obstacles”; and**
- **People with lived experience of mental health conditions should have access to the support they need to enable their participation (e.g. social security, personal assistants, flexible working, etc.)**

---

[70] http://journals.sagepub.com/doi/abs/10.4276/030802212X13470263980838
[71] http://www.tandfonline.com/doi/full/10.3109/09638237.2011.613957
[72] https://academic.oup.com/cdj/article-abstract/47/4/571/338830
[73] https://www.scottishrecovery.net/resource/sharing-the-learning-moray-wellbeing-hub/
[74] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3918008/
[75] Perkins R. UK mental health policy development – An alternative view. In: Phillips P, Sandford T, Johnston C (eds). Working in mental health: practice and policy in a changing environment. Oxford: Routledge, 2012:14-24
[76] Rapp, C. A. (1993). Theory, principles, and methods of the strengths model of case management. In M. Harris & H. C. Bergman (Eds.), Chronic mental illness, Vol. 1. Case management for mentally ill patients: Theory and practice (pp. 143-164). Langhorne, PA, England: Harwood Academic/Gordon.
[77] https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf?OpenElement
[78] http://www.tandfonline.com/doi/abs/10.1080/13691457.2012.687713
[79] https://focus.psychiatryonline.org/doi/abs/10.1176/appi.focus.20150017

Our Methodology

3

Our Methodology

In order to achieve a wide range of views from across Scotland, a survey titled "Public Life Matters 2017" was prepared using the Survey Monkey website. We believe this methodology was most appropriate to our aim of achieving as large and as geographically balanced a sample as possible.

Ideally, we would have sought views from those who are not engaged in any way with their communities. But there is simply no way to identify people who, by definition, do not have contacts. So our aim was therefore to seek the views of those involved at a low level, perhaps by having joined an organisation or subscribed to its newsletter but not playing an active role in its activities.

After piloting and refining the questions, the survey was opened for responses and publicised widely through community-based mental health organisations, social media platforms and the personal networks of peer researchers. While online completion was designed to be the primary participation method, paper copies of the survey were also distributed through local partner organisations, who then collected completed surveys and returned them to VOX for data entry. A copy of the Public Life Matters 2017 Questionnaire is available on request from VOX Scotland. Email: info@voxscotland.org.uk

The survey was open between late May and early September 2017 and a total of 249 completed responses were received. An initial analysis was then carried out by peer researchers to extract key findings and to identify areas of particular interest, or where clarification was required, for discussion by the focus groups.

In November and December 2017, peer researchers presented the preliminary statistical findings drawn from the survey to a series of six focus groups held in Elgin, Glasgow, Inverness, Paisley, Perth and Stirling.

Participants at the focus groups were mainly linked to local partner mental health collective advocacy organisations: Action In Mind, Acumen, Highland Users Group, Mental Health Network Greater Glasgow, Moray Wellbeing Hub, and Plus Perth and Kinross. The numbers of participants in each group varied from two to eight and the total number of focus group participants was 20.

Each focus group participant was given an Information Sheet and Consent Form at the beginning of the session. Peer researchers talked though all sections of the paperwork and gained prior consent, in line with agreed ethics procedures. Audio recordings were made of discussions. It was made clear to participants that while direct quotes would be used in our final report, no individual would be named or could be identified from these.

Participants were then asked to comment on a number of key survey findings and areas of interest (see Appendix A) and to relate these to their own lived experience. The feedback from the focus groups allowed researchers to re-visit the statistical findings drawn from the survey to draw a series of conclusions by bringing together quantitative and qualitative data.

Our Survey

4

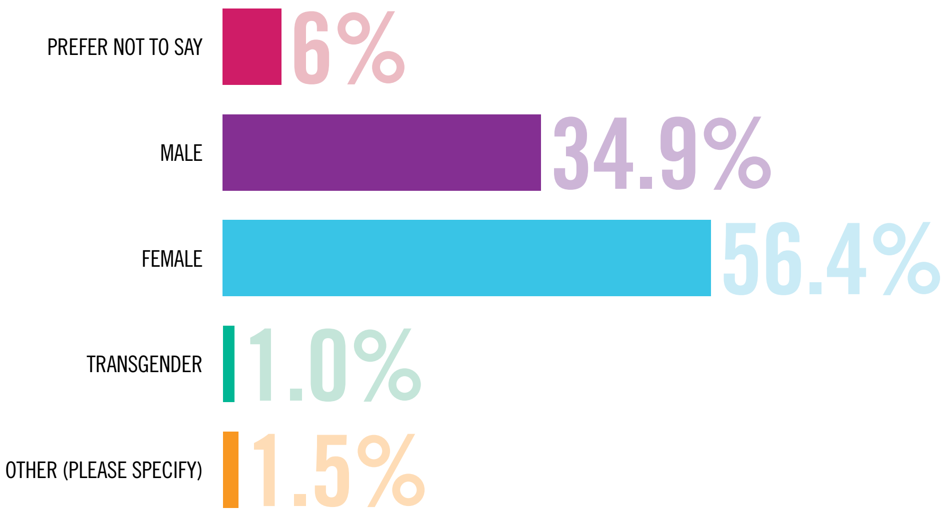
Demographics

A standard set of demographic questions was included at the end of the questionnaire. As this was not made compulsory to give the option of total anonymity to respondents, around 50 chose not to provide this information.

Gender	Responses	
Prefer not to say	6.2%	12
Male	34.9%	68
Female	56.4%	110
Transgender	1.0%	2
Other (please specify)	1.5%	3
Answered		**195**

A much higher number of females than males responded to the survey. This compares to the estimated population split in Scotland of 51.4% female to 48.6% male[80]. Numbers of those identifying as Transgender or Other were small, although in line with estimated population shares.

- **Q16: How would you describe your gender?**

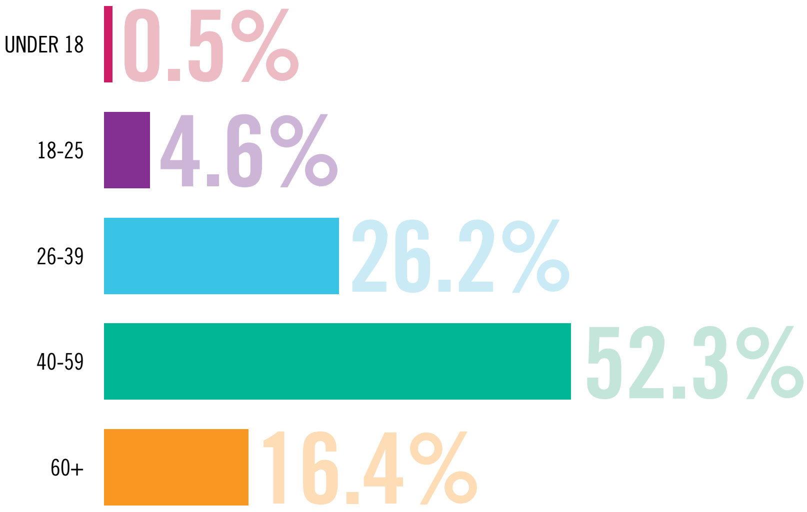


Age	Responses		Scotland 2016[81]
Under 18	0.5%	1	20.2%
18-25	4.6%	9	9.4%
26-39	26.2%	51	18.1%
40-59	52.3%	102	27.9%
60+	16.4%	32	24.4%
Answered		**195**	

---

[80] Mid-2016 Population Estimates Scotland, National Records of Scotland
[81] Mid-2016 Population Estimates Scotland, National Records of Scotland

- **Q14: What age are you?**



As the survey was aimed at adults, the low number of under 18s and the relatively high numbers of 26 to 59 year olds included is perhaps not surprising.

Sexuality	Responses	
Prefer not to say	15.0%	29
Heterosexual	72.7%	141
Gay	2.1%	4
Lesbian	1.6%	3
Bisexual	5.2%	10
Other (please specify)	3.6%	7
Answered		**194**

Precise data for the numbers of people identifying as lesbian, gay or bisexual in Scotland is difficult to obtain. Recent experimental statistics[82] show that the number of people who self-identified as lesbian, gay or bisexual in Scotland was 1.1%, which was well below the reported UK average of 1.6%. The Office for National Statistics, however, indicates that in 2016 Scotland had the largest proportion of its population identifying as LGB, with 2.2%.[83]

The data would therefore indicate that gay, lesbian and bisexual people are proportionately well represented in the survey, although absolute numbers are low.

---

[82] Integrated Household Survey, January - December 2014
[83] Statistical Bulletin: Sexual Identity, UK: 2016, ONS

Ethnicity	Responses	
White Scottish	69.0%	136
Other White British	17.8%	35
Irish	2.0%	4
Eastern European	0.0%	0
Other European	1.0%	2
Indian	0.5%	1
Pakistani	0.0%	0
Bangladeshi	0.0%	0
Chinese	0.5%	1
Caribbean	0.0%	0
African	0.0%	0
Arab	0.0%	0
Gypsy/Traveller	0.0%	0
Other ethnic group e.g. Indian Scottish, Japanese, American	9.1%	18

The population of Scotland is 96.0% white and 4.0% minority ethnic, according to both 2011 census data[84] and the 2016 Scottish Household Survey. BME numbers in the survey are small in absolute terms, but (depending on the definition of some of those who answered Other) are broadly in line with that population figure.

Question 1: Current Level Of Involvement

The opening question of the survey asked participants to assess their current level of involvement with the public life of their community by choosing one of four statements.

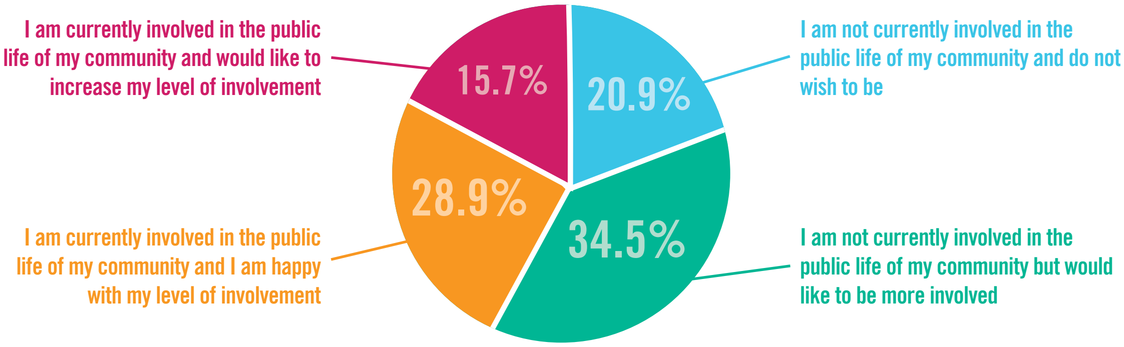
The responses were:

	All		Males		Females	
I am not currently involved in the public life of my community and do not wish to be	20.9%	52	30.9%	21	17.3%	19
I am not currently involved in the public life of my community but would like to be more involved	34.5%	86	35.3%	24	32.7%	36
I am currently involved in the public life of my community and I am happy with my level of involvement	28.9%	72	16.2%	11	35.5%	39
I am currently involved in the public life of my community and would like to increase my level of involvement	15.7%	39	17.6%	12	14.6%	16
Answered		**249**		**68**		**110**

---

[84] http://www.scotlandscensus.gov.uk/ethnicity-identity-language-and-religion

- **Q1: Which statement best summarises your level of involvement in the public life of your community?**



By Age	Under 25	26-39	40-59	60+
I am not currently involved in the public life of my community and do not wish to be	30.0%	17.7%	20.6%	28.1%
I am not currently involved in the public life of my community but would like to be more involved	40.0%	41.2%	30.4%	31.3%
I am currently involved in the public life of my community and I am happy with my level of involvement	10.0%	31.4%	27.5%	25.0%
I am currently involved in the public life of my community and would like to increase my level of involvement	20.0%	9.8%	21.6%	15.6%

In summary, 45.6% of all respondents reported to being currently involved in public life. Unfortunately, there is no readily available direct comparison figure for the population as a whole.

The Scottish Household Survey 2016[85] indicated that 27% of adults carried out some form of formal volunteering, which was defined as providing unpaid help or work to an organisation. However, this a much narrower definition of involvement in public life than that which is used here.

By gender, the level of involvement reported in the survey was much higher for females at 50.0% than for males at 33.8%. (Note: the figure for all respondents includes those who did not provide an answer to the gender question.) This is significant to a 95% confidence level using a p test, the standard used throughout this report.

Involvement was lowest in the youngest age group (under 25 at 30.0%) and highest in the 40 – 59 age range at 49.0%.

A total of 50.2% of respondents expressed a wish to increase their level of involvement in public life. This indicates that there is massive untapped potential here, with many people looking to become involved, or more involved, in their communities.

There was some difference between genders, with 53.0% of males and 47.3% of females seeking more involvement. Under 25s showed the strongest desire to increase their involvement at 60.0%, with 40-59 at 52.0%, 26-39% at 51.0% and 60+ at 46.9%.

---

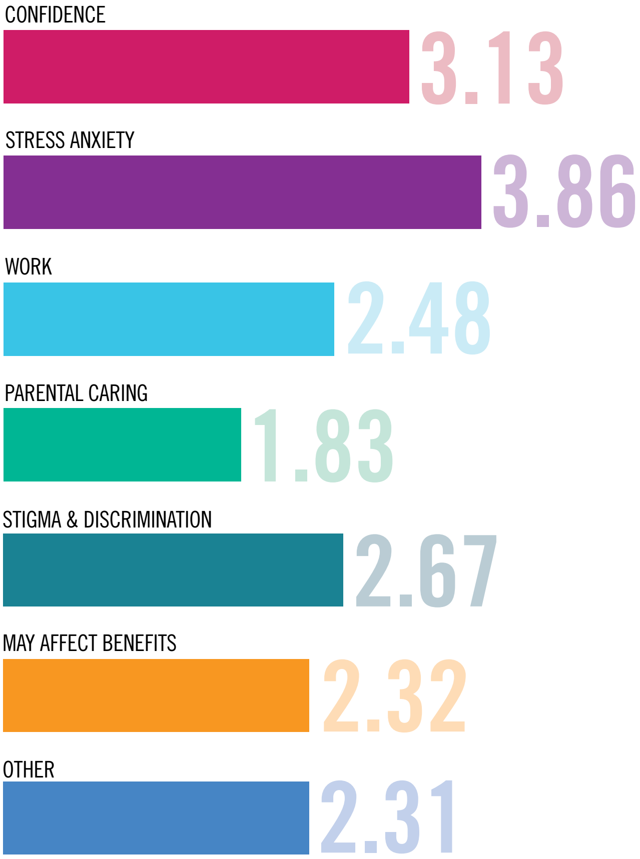
[85] http://www.gov.scot/Resource/0052/00525075.pdf

Question 2: Reasons For Non Involvement

Question 2 asked those who had reported that they were not involved in the public life of their community to rate a number of possible factors behind that response using a five point Likert scale[86] (no influence, not much influence, some influence, strong influence, very strong influence).

Influence	None	Not much	Some	Strong	Very strong	Total	Weighted average
I lack confidence	9	3	10	8	9	39	3.13
Stress and/or anxiety	5	1	7	11	18	42	3.86
Work commitments	15	1	2	6	5	29	2.48
Parental or caring responsibilities	20	0	4	4	1	29	1.83
Stigma and discrimination	10	5	8	6	4	33	2.67
May affect social security benefits	16	3	3	4	5	31	2.32
Other	9	1	1	2	3	16	2.31
						Answered	**48**

- **Q12: You said that you are not involved in the public life of your community and do not want to be. What, if any of the following might influence your decision not to be involved in the public life of your community?**



Use of weighted averages shows that the strongest factors overall were stress and/or anxiety (3.86) and lack of confidence (3.13). Results for males and females were almost identical on these factors. Stress and/or anxiety scored highest for all age groups, although all barriers were generally scored lower by the 60+ group.

---

[86] https://www.simplypsychology.org/likert-scale.html

Stigma and discrimination were not seen as major barriers, with a weighted average of only 2.67. However, it is worth noting this was much more of a factor for younger people, with average weighting of 3.67 for under 25s. We suspected this is an issue of terminology, with the terms being much more readily used amongst younger people. This issue was flagged for more detailed discussion in the focus groups.

The Scottish Household Survey 2016[87] has a section on volunteering but did not ask specifically about barriers. It did show that the majority of respondents stopped being involved in voluntary activities because of changes to their life circumstances, for example, because they no longer had the time (34%), moved (13%), through illness (10%) or had started paid employment (8%).

Question 3: Roles Aspired To

Question 3 asked those who are or wished to be involved to choose roles they aspired to from a list.

	All		Male		Female	
Volunteering for a charity, charity shop or community organization	48.9%	90	46.8%	22	48.34%	44
An activist in a campaigning/protest/ lobby group	40.8%	75	57.5%	27	34.1%	31
A trustee or director of a charity or community organization	22.3%	41	25.5%	12	18.7%	17
A board member in your children's school	6.5%	12	4.3%	2	8.8%	8
Standing for election as a local councillor, MP or MSP	10.3%	19	10.6%	5	5.5%	5
Acting as advisor for a statutory or public body	26.1%	48	31.9%	15	25.3%	23
Other (please specify)	26.6%	49	17.0%	8	34.1%	31
Answered		**184**		**47**		**91**

Volunteering was role most respondents aspired to (48.9%) followed by activist (40.8%). Most of the Other roles described general volunteering roles or "helping out" with specified activities, for example youth groups or elderly groups.

There were some gender differences: for males, activism was the top choice (57.5%) followed by volunteering (46.8%), whereas for females, volunteering was top (48.4%) followed by activism (34.1%). For under 25s, volunteering (71.4%) and activism (85.7%) were much higher than in any other group. Those aged 26-39 were more attracted to elected office (16.7%) than any other age group.

Becoming a trustee or director became more attractive as age increases. School board membership became less attractive as age increases, presumably due to the lower likelihood of having a child of school age.

---

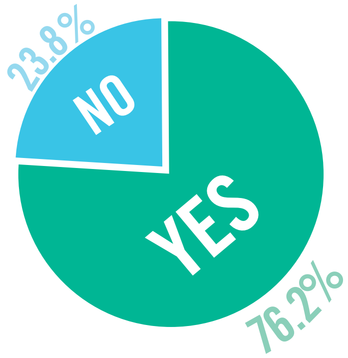
[87] http://www.gov.scot/Publications/2017/09/9979

Question 4: Social Media Use

Question 4 asked if participants used social media sites, for example Facebook or Twitter.

	All		Male		Female	
Yes	76.2%	138	59.6%	28	82.4%	75
No	23.8%	43	40.4%	19	17.6%	16
		181		**47**		**91**

- **Q14: Do you use social media such as Facebook or Twitter?**



	Yes		No		Total	
Under 25	100.0%	7	0.0%	0	4.6%	7
26-39	83.3%	35	16.7%	7	27.5%	42
40-59	75.3%	61	24.7%	20	53.0%	81
60+	52.2%	12	47.8%	11	15.0%	23
Total	75.2%	115	24.8%	38	100.0%	153
				Answered	**153**	

78.2% of all respondents who answered the question (n=181) reported using social media sites. For comparison, the Scottish Household Survey 2016[88] showed that 68% of adults in Scotland regularly accessed social media sites.

Social media use was found to be much higher in females (82.4%) than males (59.6%). Not surprisingly, the youngest age group reported 100% usage, with the figure decreasing as age increased.

Question 5: Social Media As An Involvement Tool

Those who reported that they were social media users were then asked in question 5 to choose which activities they used it for from a list.

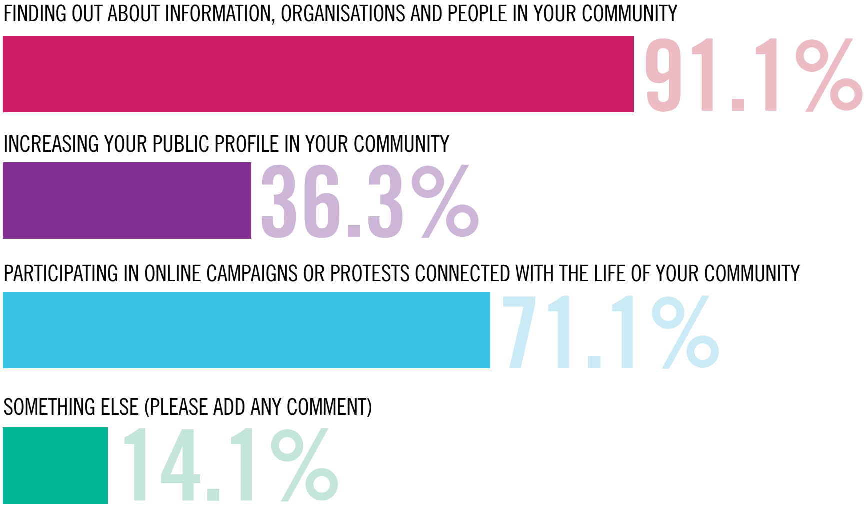
	All		Male		Female	
Finding out about information, organisations and people in your community	91.1%	123	78.5%	22	93.3%	70
Increasing your public profile in your community	36.3%	49	35.7%	10	37.3%	28
Participating in online campaigns or protests connected with the life of your community	71.1%	96	67.9%	19	77.3%	58
Something else (please add any comment)	14.1%	19	14.3%	4	13.3%	10
		135		28		75

All answers show higher female than male rates of usage, reflecting higher overall social media usage amongst women than men.

---

[88] http://www.gov.scot/Publications/2017/09/9979

- **Q5: You have told us that you use social media such as Facebook or Twitter. Have you, or would you consider using social media for any of the following activiites? (Tick all that apply)**

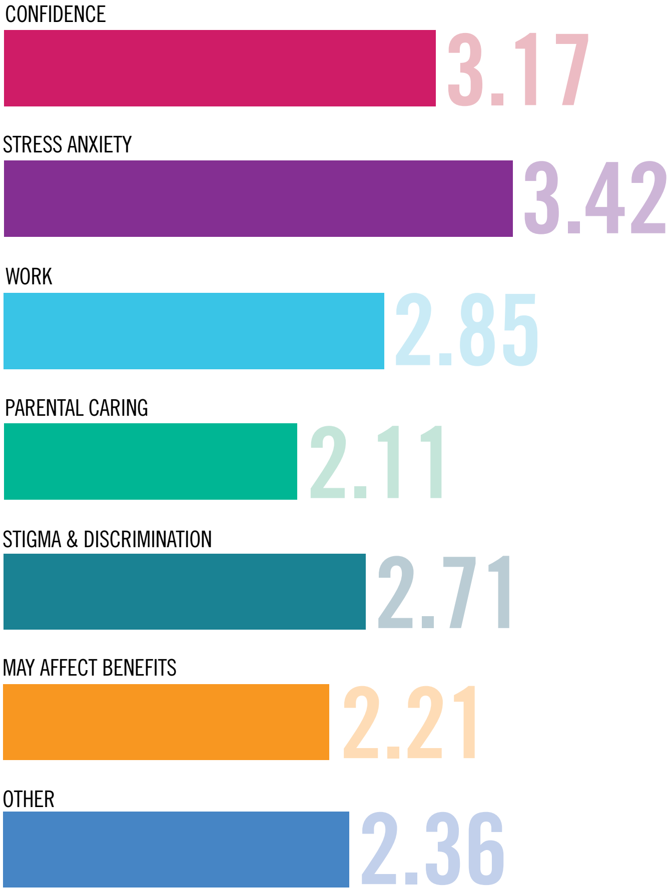


Question 6: Barriers To Involvement

Question 6 turned to factors that may inhibit future involvement, asking participants to rate the influence of a list of possible barriers, again using a five point Likert scale (no influence, not much influence, some influence, strong influence, very strong influence).

ALL	No	Not much	Some	Strong	Very strong	TOTAL	AVE
Lack confidence	22	25	51	38	30	166	3.17
Stress and/or anxiety	15	16	50	45	34	160	3.42
Work Commitments	49	13	34	37	25	158	2.85
Parental or caring responsibilities	85	19	24	15	16	159	2.11
Stigma and discrimination	44	29	41	23	24	161	2.71
May affect social security benefits	86	11	26	14	22	159	2.21
Other	40	3	6	9	14	72	2.36
						Answered	**174**

• Q6: How much influence might the following have in preventing you from increasing your current level of involvement in the public life of your community?



MALE	No	Not much	Some	Strong	Very strong	TOTAL	AVE
Lack confidence	6	7	10	7	16	46	3.43
Stress and/or anxiety	5	3	8	13	13	42	3.62
Work Commitments	18	7	4	9	2	40	2.25
Parental or caring responsibilities	25	4	3	5	2	39	1.85
Stigma and discrimination	11	3	10	7	11	42	3.10
May affect social security benefits	18	3	9	3	8	41	2.21
Other	12	0	0	3	5	20	2.45
						Answered	**46**

FEMALE	No	Not much	Some	Strong	Very strong	TOTAL	AVE
Lack confidence	10	12	29	25	10	86	3.15
Stress and/or anxiety	7	8	27	26	17	85	3.45
Work Commitments	21	5	23	20	16	85	3.06
Parental or caring responsibilities	46	6	16	6	12	86	2.11
Stigma and discrimination	26	16	22	12	11	87	2.61
May affect social security benefits	50	6	12	5	12	85	2.09
Other	21	2	4	3	8	38	2.34
						Answered	**87**

Stress and anxiety (3.42) was seen as the strongest barrier followed by lack of confidence (3.17). These two factors were the highest rated for both males and females

Work commitments score higher for females than males (3.06 to 2.25) as did parental or caring responsibilities (2.11 to 1.85). Fear that involvement might affect social security benefits was a slightly stronger barrier for males (2.21 to 2.09).

Almost all barriers affected younger people more than older people; the exceptions being parental/caring responsibilities and benefits fears.

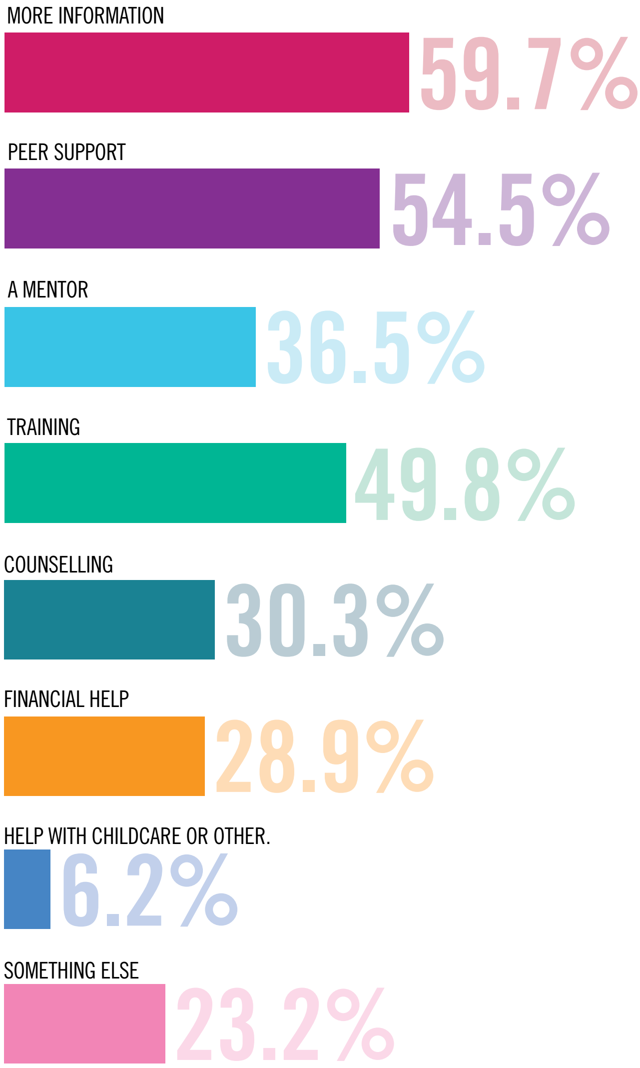
One of the Other barriers mentioned was public transport, and the example of difficulties in attending evening meetings or activities was mentioned several times. This was flagged for further discussion in the focus groups to examine whether this was a general issue or one that only, or primarily, affected certain locations, such as rural areas.

Question 7: Support

Question 7 asked what support would assist participants to become more involved in their communities, with a number of potential options listed and respondents asked to choose all that they felt applied.

	All		Male		Female	
More information and advice about the possibilities open to me	59.7%	126	53.0%	36	64.5%	71
Peer support from other people with mental health problems who are active in civic and public life	54.5%	115	60.3%	41	52.7%	58
A mentor (personal advisor and supporter) in the organisation I work for	36.5%	77	29.4%	20	42.7%	47
Training for the role(s) I aspire to	49.8%	105	41.2%	28	55.5%	61
Counselling provided by my local mental health team	30.3%	64	29.4%	20	34.6%	38
Financial help to cover transport, training costs and/or supplement or replace current income/ benefits	28.9%	61	26.5%	18	30.0%	33
Help with childcare or other caring responsibilities	6.2%	13	3.0%	2	7.3%	8
Something else (please add any comment)	23.2%	49	32.3%	22	20.9%	23
		211		**68**		**110**

• Q7: What support would help you to become involved in the public life of your community? (Tick all that apply)



Information and peer support were the most needed supports overall. Peer support was top for males (60.3%), while more information was top for females (64.6%).

Mentoring (42.7% to 29.4%) and training (55.5% to 41.2%) scored significantly higher for females than males.

Financial help was not seen as a major need, apart from for under 25s, where it scores 55.6%: twice as high as for any other age group.

Question 8: Participation In Elections

Question 8 asked whether participants voted or played an active part (i.e. helped to campaign or stood for office) in a number of recent national and local elections.

	All		Male		Female		Actual Turnout
Scottish Referendum, 2014	81.3%	170	79.4%	54	84.6%	93	84.6%
UK General Election, 2015	73.2%	153	75.0%	51	74.6%	82	71.1%
Scottish Parliament Election, 2016	73.2%	153	70.6%	48	78.2%	86	55.6%
Local Council Elections, 2017	71.8%	150	73.5%	50	73.6%	81	46.0%
Answered		**209**		**68**	**110**		

	Scottish Referendum	UK General Election	Scottish Parliamentary Election	Local Council Elections
Under 25	88.9%	77.8%	88.9%	66.7%
26-39	82.4%	76.5%	76.5%	68.6%
40-59	81.4%	73.5%	69.6%	74.5%
60+	81.3%	75.0%	81.3%	78.1%

Only the Scottish Independence Referendum showed a lower overall participation rate from survey respondents than the actual recorded Scotland wide turnout, with all others being higher.

Female participation was higher than for males in the Independence Referendum (84.6% to 79.4%) and the Scottish Parliamentary election (78.2% to 70.6%). Figures for male and female participation in the UK General Election and the Local Council elections were almost identical.

Younger people, i.e. under 25 and 26-39, scored highest on the Scottish Independence Referendum and the Scottish Parliamentary election.

Reported turnout in Local Council elections scored very highly relative to the actual turnout figure across all age groups, with the level of participation increasing with age.

Question 9: UK General Election, 2017

Question 9 asked separately about voting or participation in the UK General Election held on 8 June 2017. This question was worded slightly differently from Question 8, as some participants would have answered before election day, with most responding afterwards.

	All		Male		Female		Actual Turnout
I did not vote or take active part	16.0%	33	15.2%	10	15.6%	17	
I voted	78.6%	162	75.8%	50	80.7%	88	66.4%
I took an active part	5.3%	11	9.1%	6	3.7%	4	
		206		**66**	**109**		

	Under 25		26-39		40-59		60+	
I did not vote or take active part	10.0%	1	15.7%	8	21.0%	21	0.0%	0
I voted	90.0%	9	80.4%	41	73.0%	73	93.6%	29
I took an active part	0.0%	0	3.9%	2	6.0%	6	6.5%	2
		10		**51**		**110**		**31**

The total turnout recorded was higher than the actual turnout figure for Scotland. More females reported voting than males, while more males took an active part in the election campaign than females.

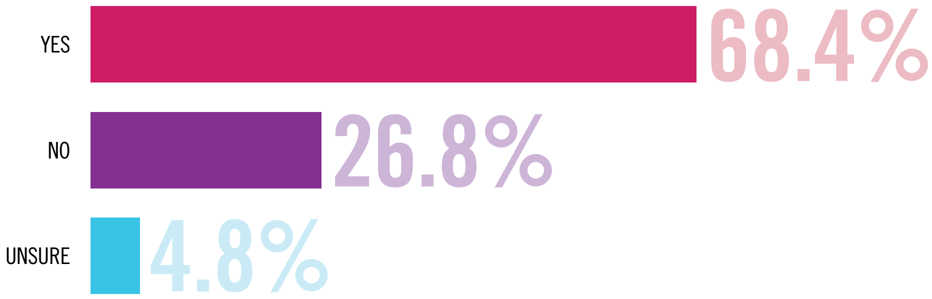
Under 25s (90.0%) and 60+ (93.6%) were more likely to vote than the two middle age ranges.

Question 10: Petitions

Question 10 asked whether participants had signed a petition, including an online petition, in the previous two years.

	All		Male		Female	
Yes	68.4%	143	58.8%	40	77.3%	85
No	26.8%	56	35.3%	24	17.3%	19
Unsure	4.8%	10	5.9%	4	5.5%	6
Answered		**209**		**68**		**110**

- **Q10: In the last two years have you signed a petition (including online petitions)?**



	Yes		No		Unsure	
Under 25	80.0%	8	20.0%	2	0.0%	0
26-39	78.4%	40	13.7%	7	7.8%	4
40-59	67.7%	69	28.4%	29	3.9%	4
60+	59.4%	19	34.4%	11	6.3%	2
Total		**136**		**49**		**10**

Females were far more likely to have signed a petition than males (77.3% to 58.8%).

Under 25s were the most likely age group to participate (80.0%). Participation rates fell as age increased, perhaps in part due to lesser social media usage.

Question 11: Barriers

Question 11 gave participants the option to summarise the barriers that might prevent them from becoming involved in public life. 156 respondents answered this free-text question. Responses were thematically analysed, and the following potential barriers were found to be the most common. It should be noted that some responses cited multiple potential barriers.

Self-confidence	38	28.2%
My mental health	30	22.2%
Lack of time/other commitments	22	16.3%
Anxiety	18	13.3%
Stigma and discrimination	18	13.3%
Lack of information	12	8.9%
Organisations not open or welcoming	11	8.2%
Lack of support	10	7.4%
Money/benefits issues	10	7.4%
Physical disability	8	5.9%
Transport	5	3.7%
Age	3	2.2%

Self-confidence and the impacts of living with a mental health condition were the most commonly mentioned barriers. This latter factor included both the symptoms experienced making it difficult to become involved and also the fear of future episodes making participants reluctant to commit to a regular activity in case they became unable to participate at a later date.

While many of the factors could be classed as internal (i.e. self-stigma, fear of letting people down, etc.), it should also be noted that the perceived attitude of community organisations was a factor for many participants. This included respondents' perceptions of both a general reluctance to welcome new members and also a particular fear of stigma relating to mental health conditions.

Some quotes illustrate the key barriers:

"It's very difficult to find out about opportunities in my area, there isn't a central point of accessing information and it is often scattered or advertising is left until last minute and sometimes I find out about things I might've liked to get involved with after the fact."

"Members of particular groups can be quite secretive and unless you know someone on a committee you're not likely to find things out."

"I have Generalised Anxiety Disorder and commitment is a problem for me as I never know how I'm going to feel from one day to the next. Panic and anxiety symptoms will lead me to think that I would be useless and fail at what I'm planning to do or make things worse for others."

"Lack of money, on a low income. [I'm] self-employed, so any voluntary work means loss of income, so poverty trap."

"Stigma about the mental health issues I have experienced in the past and people's attitudes to "outsiders" becoming involved in community activities."

"The stigma - the almost universal assumption that if one suffers from depression one must be ill-educated and stupid."

"Confidence in myself, fear of taking on too much, which in turn would affect my mental health."

Question 12 & 13: Impact Of Completing The Questionnaire

Questions 12 and 13 asked about the impact of completing the survey on participants' views in relation to involvement in public life. These were added at the request of DRILL.

Firstly, participants were asked to rate the extent that completing the survey had made them aware of opportunities for involvement in their community, using a scale of 1 to 10 (1 being the lowest and 10 the highest).

	Total	Weighted Average
All	201	4.95
Male	68	4.82
Female	110	5.24

	Total	Weighted Average
Under 25	10	5
26-39	51	4.65
40-59	102	5.11
60+	32	4.88

Males felt slightly more aware of opportunities for involvement than females (5.24 to 4.82 weighted average). Under 25s and 40-59 scored 5 or above, whereas 26-39 and 60+ scored under 5.

Participants were then asked in question 13 to rate the extent that completing the survey had increased their interest in becoming involved their community, using a scale of 1 to 10 (1 being the lowest and 10 the highest).

	Total	Weighted Average
All	201	5.01
Male	68	4.96
Female	110	5.32

	Total	Weighted Average
Under 25	10	6.5
26-39	51	4.94
40-59	102	5.08
60+	32	4.34

Females felt the survey improved their interest in becoming involved more than males (5.32 to 4.96 weighted average). Under 25s scored much higher than average, whereas 60+ scored much lower.

Our Focus Groups

5

Introduction

In November and December 2017, peer researchers presented the preliminary statistical findings drawn from the survey to a series of six focus groups held across Scotland. An outline of the focus group structure is included as Appendix A.

The number of participants in each group varied from two to eight and the total number of focus group participants was 20. This section of the report brings together key common findings from across the six groups, taken from detailed analysis of the full transcripts of all group discussions.

What does taking part in the community mean to you?

For the majority of participants, taking part in the community means volunteering. Virtually everyone stated that it is potentially a positive and empowering experience.

> *"Being part of a community makes me feel like I belong somewhere."*

> ***"Being accepted. Being trusted. It keeps me well. It keeps me out of hospital. It gets me out of the house and keeps my brain busy."***

> *"[It means] inclusion – the realisation that the stigma isn't there, that [the people you meet] are more aware of your problems and adapt to them."*

> ***"I've volunteered in a variety of ways because I wanted to move on. I wanted to feel secure in myself, I wanted to be involved rather than sitting in my house watching television all day. I decided that I was going to make a life for myself and getting out into the community was a big part of this."***

> *"I've been part of so many different things and, honest to God, it is the best thing for my mental health problems in years."*

> *"It's good for your neural pathways. They say, do something that is new and challenging."*

What roles are involved?

The findings of the survey were largely borne out by the activities participants in the focus groups stated they undertook.

Although the majority were engaged in basic volunteering in organisations directly connected with their own mental health conditions, seven out of 20 were in positions of trust in broader civic and community bodies.

Sitting on the board of a local community trust, being a welfare rights officer, sitting on a residents' committee, being a scout leader, sitting on a school board, sitting on the board of a mental health charity and being a director of the local housing association were the roles of past or present experience cited specifically by individual participants.

In addition, two participants were actively involved in local or national politics. One is a political education officer for a political party branch and is planning to stand as an MP or MSP for their constituency. The other had been elected as local authority councillor earlier in the year.

What barriers are encountered?

A cross section of all the potential barriers highlighted in the survey were experienced by one or more participants in the groups. These include:

Self-stigma

> *"I have a very chaotic mind. I can barely function to the point where I don't know what to buy for food. I'm frittering away money away to the point where I don't know what money I have at the end of it. My mum has been giving me shopping cards from the word go, I've relied on her so much that I've forgotten how to rely on myself. [How on earth could I hold a responsible position in the community?]"*

> ***"I have an episodic illness. At times, I am capable of working, at times I am not. I am reluctant to step up because I am not sure I can provide the continuity."***

"When I was unwell, I didn't want to meet people and the more interesting they were, the less I wanted to meet them because I thought I couldn't cope intellectually"

"I'm not a leader. I was a very shy child. I would be at the back, I would be only second in command."

Perceived or actual stigma in the community

"I was on the residents' committee. I know that if I revealed I had a serious and enduring mental health problem they would ignore everything I said."

"I've been on our community council for a few years and you need to hide your condition because you would become a target otherwise."

I'd love to be a councillor, but I know that people knew I had a mental health problem I wouldn't have a chance in hell of getting elected."

"I've been involved in my wee boy's school, but it is in the more affluent part of town and you definitely could not say that you had a mental health problem. It has limited what I can do there."

"People don't accept you. They look at you in strange ways when you say you've got a mental health problem."

Unanticipated financial costs

"I was elected councillor earlier this year. Once elected, I received a regular income for undertaking my responsibilities, but the process of getting elected was costly for someone who was then on benefits. I only received a limited sum to help me with my campaigning activities and I had to cover the cost of registering and travelling to the party conference. Most other councillors were retired on a pension or had a paid job and little consideration was made about my own financial circumstances."

Time constraints

"There is the issue of the time and energy it takes. If you have used up all your energy and your capacity to cope day to day, there is no room left for volunteering."

Other Issues

In addition, focus group discussions placed greater emphasis on a number of other issues than was found from the survey responses.

The perception or reality that volunteering or playing more responsible roles in the community might detrimentally affect an individual's social security status was cited by nearly all participants as a possible constraint on their willingness or ability to become active in their communities.

Comments included:

"I work as a Welfare Rights Officer for the Citizens Advice Bureau. Therefore, I have read maybe 300 assessment reports and I can honestly say that two thirds of them have ridiculous comments like, someone works in a charity shop and is therefore capable of work, etc. Coping with being a single parent with a disability has taught me how difficult it is to fight the system over and over again."

"There are people I know that are seriously ill and because they are trying to make some contribution to their community they are having their benefits taken away."

"I have a friend who winds up in hospital every time she gets a benefits review. She appeals and always wins on appeal but the rigmarole, stress and time in hospital sucks up time and energy that could be more usefully applied in the community."

A number of participants commented that the selection process for voluntary posts had become more difficult in recent years, to the point where they can be as rigorous and demanding as those used for paid jobs.

Comments included:

"I've trained in an established mental health field. I recently tried to get a voluntary role because of my fluctuating health and encountered onerous recruitment procedures that are pretty much the same as I encountered as an employee."

> *"I've worked in the voluntary sector as well and there does seem to be a barrier in the paperwork that is involved. Even charity shops now want the same commitment as they do from paid employees and this is putting off a lot of potential recruits."*

Finally, it is worth highlighting the problems that one participant encountered when she was appointed to the board of her local Community Council. She suffers from anxiety and depression, brought on partly by domestic abuse, and she found the confrontational style of decision making difficult to cope with.

> *"I became very stressed out, almost like a deer in the headlights. I stopped listening and taking in information that was probably pertinent. I didn't pick up on the subtleties or clues in the way people were trying to engage me. The main problem, however, was that whenever I put ideas across they were dismissed and then I felt unable to participate. I find it difficult with confrontation, so I backed out of it. I had a very similar experience sitting on the school council when new and more forthright parents joined. I just couldn't cope with it."*

What helps overcome the barriers?

Obtaining the correct information, as found in the survey, featured in the focus group discussions. As one participant put it:

"There is a constant need to publicise information. A lot of people have no interest in taking part in the community until they see or hear something. Flyers, adverts, posters are all important."

Online information was seen as equally important. But the challenge cited by some participants was not that the information is not available but that it is difficult to access when your concentration is impaired.

> *"I can go online but I get confused. I need someone to help me, somebody at the library who could say, "do you need a helping hand?"*

"Getting information out of the system is very difficult. Phoning up and asking is hard if you're frightened and stressed."

Related to this was the strongly expressed feeling that mentoring, which most participants equated with peer support, was critical in helping people with lived experience adjust when taking on new civic or community responsibilities.

The need for mentoring and peer support was articulated most eloquently by a community worker with lived experience:

> *"I think working in the community effectively is impossible without mentors and without being encouraged to shadow and support people with mental health problems. The whole point about being a user is mentor and support and encourage and train. Allowing people to watch how it is done and join in is where people learn about themselves, learn about their own way of understanding themselves, learn about ways of coping and learn about ways of doing things in their own way."*

The role of social media

The role of social media in providing essential information, supporting people and allowing people to engage in community and political activity was much discussed in the focus groups.

One participant took an active part in the Scottish Independence Referendum using Facebook and other social media outlets and explained how it helped to keep her feeling engaged in the community during times when she was not active in other ways:

> *"I didn't encounter any stigma. When you've not got a job and people are judging you because of that, you feel you are contributing something to society and feel you are doing something worthwhile."*

Another participant found social media to be a good way of staying in touch with his local community group when his condition grounded him at home or restrictions to travel in a rural area prevent him from attending meetings:

> ***"For me, social media is a positive thing. I sort of drift in and out of [my group] but because I am on social media, I can always keep up with what's happening. If [my group] is making an appeal online or posting a quick question in advance of meetings, I can respond to that even if I am not able to attend [– and I still feel involved]."***

Others found the format and restrictions of social media frustrating:

> *"The unit of information [by which people learn about society] has now been reduced from an article or book to a soundbite text. In the past, you'd read a book to find out about a topic you are interested in, now you expect to get the same amount of information from 150 characters on Twitter. Things are simplified to the point of disinformation and this has a direct effect on the issues we discuss in the community."*

Advice

Focus group discussions all concluded with an appeal for advice – to other people with lived experience and to policy makers.

To policy makers:

> *"Sit down and listen."*

> ***"Have first aiders in all buildings, someone who is there to administer in a [mental health] crisis and act as a central point of information"***

> *"Having an MP or MSP advocating for the good that is going on within the local community and getting them to prompt it nationally [is what we need]"*

To people with lived experience:

> *"Let other people see what mental health is all about. Bang at doors with your story. We're too insular."*

> *"Be brave and try new things. If you don't go and try it you will never know whether you enjoy it. There are things that you might think you would never be able to do, like public speaking, that could open new doors for you."*

> *"Learn something new. It's good for your neural pathways. I always wanted to learn to play the piano and I started Grade 1 this year. Anything that challenges you is good."*

> ***"Go for it, whatever IT is. Don't worry about what other people think of you." "I'd say to people, 'go ahead', it's the best thing I've ever done."***

Discussion

6

Introduction

We recognise that those who responded to our survey formed a self-selected sample rather than a scientific cross section. But those who did participate could be argued to be more likely to be already involved in their communities rather than less – they would have come into contact with the survey through existing memberships of mental health organisations or subscriptions to relevant social media pages. This makes the high proportion reporting multiple barriers to involvement all the more relevant: their responses are likely to be based on direct experience.

While we would not attempt to argue that the exact percentage figures we quote are necessarily representative of all people with lived experience of mental health conditions, we are very confident in our primary research finding:

A large percentage of people with lived experience of mental health conditions would like to become involved, or to get more involved, in their communities. This represents a tremendous untapped potential for our civic and public life.

Indeed, as our sample consisted of people already likely to be more involved in their communities than average, it could be argued that this high level of untapped potential we have identified is, if anything, an underestimate.

Our Research Findings

Our project aimed to investigate four research questions. These are set out below with the results from both our survey and our focus groups being brought together under each. This analysis of both quantitative and qualitative data leads us to draw conclusions in each area.

1. **What proportion of people with lived experience of mental illness would like to increase their engagement with civic and public life?**

   Overall, 50% of the total survey sample (n=249) would like to become involved, or more involved, in their communities. There was some difference between genders, with 53% of males and 47% of females seeking more involvement, although both figures are high.

   We have shown that half our sample would like to become involved, or to get more involved, in their communities. This primary research finding represents a tremendous untapped potential for our civic and public life.

   Under 25s showed the strongest desire to increase their involvement at 60%, with 40-59 at 52%, 26-39 at 51% and 60+ at 47%. This is very interesting, as many organisations repeatedly report low levels of engagement amongst younger people.

2. **What civic/public roles do they aspire to?**

   The most popular roles sought were those of volunteer (49%) and activist (41%). There were some gender differences: for males, activism was the top choice (58%) followed by volunteering (47%), whereas for females, volunteering was top (48%) followed by activism (34%). For under 25s, volunteering (71%) and activism (86%) were much higher than in any other age group.

   Discussions at our focus groups reinforced the view of researchers that the term “volunteer” was being used in a relatively informal sense by most people. They were not referring to taking up a formal volunteering position within an organisation, but instead talked of “helping out” or assisting in activities in a wide range of organisations, such as those caring for older people or providing opportunities for young people. The primary driver of potential involvement was simply to help others.

   22% expressed a desire to become a trustee or director of a charity or community organisation. This seems like a relatively high figure given that many community organisations with large memberships tend to find these roles difficult to fill.

   Similarly, the figure of 10% interested in seeking election to public office also stands out as relatively high. We suspect that both these results are likely to be related to the sample population being more involved in community life than average.

   However, they do indicate a level of desire to become involved at all levels.

3. **What barriers prevent them from playing a more active role in civic and public life and what are the potential solutions to overcome them?**

The strongest barriers reported were stress and/or anxiety (3.9 weighted average on a five point Likert scale) and lack of confidence (3.1). Scores for males and females were almost identical on these factors. Work commitments score higher for females than males (3.06 to 2.25) as did parental or caring responsibilities (2.11 to 1.85).

Stress and/or anxiety scored highest for all age groups, although all barriers were generally scored lower by the 60+ age group.

There was considerable discussion about barriers in our focus groups and this greatly illuminated our thinking. While stigma and discrimination scored relatively low amongst our survey participants (2.67), we suspected that this was in part due to many people not using or recognising the technical term.

In the groups, participants talked of a number of different barriers that would routinely be classed as resulting from stigma and discrimination, yet without using this specific wording. Some questioned their own ability to become involved as a result of their mental illness, a form of self-stigma. Others stated they had the ability to contribute effectively when well but did not feel able to make a long-term commitment due to a fear of letting others down because of a future occurrence of their condition, a particularly common view amongst those with episodic diagnoses.

Several participants expressed what can be called anticipated stigma as a barrier to future participation – a fear that the response they would receive from others would be stigmatising in relation to their mental health condition. This was articulated as an expectation of being ignored or of their contributions being viewed as devalued.

Indeed, several participants stated that they could only imagine becoming involved in community life or standing for election if they hid their mental health history.

It is also worth noting that securing formal volunteering roles was seen as more difficult that it perhaps was in the past. Formal entry requirements and onerous recruitment and selection processes were cited as a barrier, with several focus group participants describing it as comparably difficult to applying for paid employment.

Practical issues are also important barriers for many people. Lack of time is a key consideration, particularly from those already coping with work, family life and caring responsibilities on top of living with a mental health condition. This was a bigger issue for women, presumably as they are the main caregivers in many families. Lack of public transport can also be a barrier, particularly in the evenings, when many meetings and activities take place. This is felt even more acutely in rural areas but can also be a barrier in towns and cities.

Lack of financial assistance was not seen as a major barrier within our survey, but it was referenced in focus groups. There was a specific fear from those on the various forms of sickness or disability entitlements that participation in any level of volunteering activity would been taken as evidence of their fitness for full time work.

When asked what support would assist towards greater involvement in their communities, more information and advice came top (60%). Focus group discussions also showed that many people simply do not know where to find out about potential activities and opportunities within their communities. When questioned about activities that they had become involved in, many reported first hearing of groups or activities at meetings or through other existing involvement, either from workers or other participants. This shows that those already involved have a distinct knowledge advantage here, with those on the outside often unable to find a way in.

Online information sources were seen as useful for some people but not relevant for others. Many participants reported a clear preference for having a physical place to go to source information and advice where they could speak directly to someone, rather than simply being referred to a web site or given leaflets or flyers.

Outreach approaches were also welcomed, where staff or volunteers directly promoted opportunities or activities to those who might have an interest in participating.

Peer support (54%), mentoring (37%) and training (50%) also scored highly. Mentoring (43% to 29%) and training (56% to 41%) scored significantly higher for females than males.

Discussion at the focus groups clarified that what seemed to be required was not necessarily formal peer support or mentoring/befriending programmes but simply assistance and encouragement from another person to become involved. Indeed, many people saw mentoring and peer support as essentially the same thing.

Several participants reported that they would not consider attending a new group or activity on their own but would potentially go along with someone else. This ties in with emerging interest in the value of interconnectedness on wellbeing. For those who had become involved, the initial support of a friend or acquaintance was often a key enabling factor.

Financial help was not generally seen as a major issue, apart from for under 25s, where it scores 56%: twice as high as for any other age group.

Traditional mental health services were generally not seen as a good source of support for community involvement. This is very much at odds with several policy initiatives that stress the value of involvement and social activity in recovery. Clearly there is work still to be done to make this a reality in the lives of communities.

4. What policy initiatives could be put in place to overcome these barriers?

Many suggestions were made during the focus groups. These were not phrased as proposed policy initiatives, a language that most people would not use, but rather as advice to those in positions of power or influence. All participants who had become involved in their communities were convinced of the benefits to others and for themselves. The often-repeated advice for anyone thinking of becoming involved was simple and straightforward: “Go for it!”. This is a message that was seen as positive and encouraging and could be used as part of public information campaigns to promote community involvement.

Several clear needs to overcome barriers to initial involvement were identified and tackling these formed the core of several suggested actions. Public information points, perhaps in libraries or other public buildings, with information and advice on opportunities and activities and people to talk to about them, was mentioned several times. The provision of direct support from another person to join in and to build up confidence was also frequently discussed. Support when in a new role was also seen as a requirement.

It was also stressed several times that some change is also required from community groups and organisations if they are to attract new involvement. In several areas existing organisations were perceived to be something of a closed shop or dominated by cliques who had been in positions of power for considerable lengths of time. Styles of discussion and debate in organisations like community councils and residents’ associations were felt to be confrontational and not attractive to new or less experienced people.

It should also be stressed that several participants were already active within mental health organisations but also wished to become involved in wider community life.

Anticipated stigma and, in some cases, personal experiences of direct discrimination are a key barrier for them.

There is therefore a need for many community organisations to consider their awareness of the needs of people with lived experience of mental health conditions, and indeed their attitudes towards mental illness, if they are to become truly open to all. As well as becoming more representative they would also benefit from increased involvement and the addition of a new and often different perspective to their discussions.

Other Issues

Our findings in two other areas are also worthy of note.

Use of technology

There was a high level of social media use reported amongst survey respondents, especially amongst younger people, as might be expected. 76% used social media sites overall, rising from 52% in over 60s to 100% of under 25s. 91% of social media users reported using sites as a source of information and 71% reported participating in an online campaign.

In the focus groups, however, discussion indicated that most participants used social media primarily for personal use (interacting with family and friends). Some did not go online at all and did not have any interest in doing so. This indicates that online methods of participation are very useful for some people but can never be used as the sole means of engagement.

Democratic participation

Questions in the survey about voting or being active in various recent elections showed a very high level of participation. Again, it is worth noting that this was a self- selected group who may well have a higher level of engagement than the community in general.

Only the Scottish Independence Referendum showed a lower overall participation rate from survey respondents than the actual recorded Scotland wide turnout, a difference of -3%. General elections showed a higher rate of participation, +2% in 2015 and +12% in 2017. It should be noted, however, that some participants will have completed our survey before the 2017 general election and were therefore reporting an intention to vote rather than a definite confirmation that they had participated.

For the Scottish Parliament election in 2016 the sample was much more likely to have voted with a difference of +18%. The difference for the local council elections in 2017 was +25%, a massive difference and perhaps indicative of a more involved sample with a much greater interest in local affairs than average.

Conclusions

The key finding from the survey is that half of all participants would like to increase their level of involvement in the public life of their communities. At a time when third sector organisations are almost universally reporting relatively low rates of participation, this is a staggering result. There is clearly a great deal of potential to grow involvement and to bring the skills and talents of people with lived experience of mental health conditions into public life.

Lack of confidence, stress and anxiety and a lack of information about potential involvement opportunities were found to be major barriers to increasing involvement.

More information about potential opportunities, the provision of training for new roles and the use of both peer support and mentoring were found to be potential solutions to tackling these barriers. However there also needs to be change within community organisations and efforts made to become both more open to new participation and more aware and accomodating of the needs of people with lived experience.

Our Recommendations

7

Our recommendations

Our research has identified specific barriers that act to prevent people with lived experience of mental health conditions from playing a full role in the public life of their communities. We have also identified several areas where greater support can be put in place to overcome these barriers.

We discussed all of these issues as a group and identified a set of explicit policy recommendations. In each case we have directed these to a specific organisation, or class of organisations, that has responsibility in the relevant area and who we would look to lead on the issue.

Many of our recommendations are consistent with current public policy at Scottish, UK, European and international levels. We believe that their implementation would promote the goal of enabling people with lived experience of mental health conditions to realise their rights as full members of civic and public society.

Scottish Government

The Scottish Government should ensure the Local Governance Review[89] engages directly with people with lived experience of mental health conditions.

This will identify additional barriers and solutions, as we have done, and enable work to co-produce solutions and recommendations to feed into the review.

The Scottish Government should audit Participation Requests[90] by geography and community of interest or identity.

As Participation Requests are intended to be used a last resort, this will give an indication of where traditional engagement mechanisms and opportunities to influence decision-making are either absent or substandard.

Local Authorities

Local Authorities should adhere to the National Standards for Community Engagement[91] and evaluate the impact of engagement, whilst also regularly auditing the resource they invest and the extent to which it facilitates participation and civic engagement.

This could be assessed, for example, through:

- participation in local democracy;
- influence over local decision making;
- confidence and skills among local people;
- social capital;
- number and diversity of people volunteering in their communities; and
- satisfaction with quality of life in the neighbourhood.

Local Authorities should invest in staff capacity to enable increased community engagement, including that of seldom heard groups, and monitor diversity and impact.

Staff and resources must be made available to promote engagement mechanisms and opportunities to influence decision making and to support local peer leadership. This includes building community capacity to engage in formal mechanisms such as Asset Transfers and Participation Requests.

Local Authorities should ensure third sector and community groups are inclusive in relation to mental health.

Promoting equality of inclusion in the work of local third sector and community groups should be a key priority for Community Learning and Development services and/or other local authority staff with responsibility for building community capacity.

---

[89] https://beta.gov.scot/policies/improving-public-services/local-governance-review/
[90] https://beta.gov.scot/policies/community-empowerment/participation-requests/
[91] http://www.voicescotland.org.uk/media/resources/NSfCE%20online_October.pdf

Healthcare Improvement Scotland

Healthcare Improvement Scotland's iHub's Practice Administrative Staff Collaborative should test models to up-skill practice staff.[92]

This would include enhancing skills to:

- Address underlying attitudes and behaviours that may hinder effective and appropriate 'triaging';
- Appropriately 'triage' to the correct member of the multi-disciplinary team, including through enhancing staff mental health literacy;
- Appropriately signpost to community assets;
- Signpost to resources that support self-management; and
- Increase the number and quality of community connections (as identified by social capital[93] or sense of belonging) that people referred have.

Health and Social Care Partnerships

Health and Social Care Partnerships should identify, through Primary Care Improvement Plans, opportunities for links workers within GP practices and volunteers to enable participation in communities, including 'proactive signposting', where they support people to attend appointments or community groups, etc.

As part of the implementation of the 2018 GMS Contract in Scotland[94] and A Connected Scotland[95] these plans should include working with communities and the third sector to enable gaps in community assets and self-management resources to be identified and addressed, as exemplified by Health Connections Mendip[96] in the Compassionate Frome project. These outward connections, where appropriate, should be non-mental health specific and enable the integration of people with lived experience of mental health conditions into the wider community.

Health and Social Care Partnerships and Community Planning Partnerships should identify opportunities for Advice and Advocacy Workers to be based within Primary Care and Job Centre settings.

Learning from the Building Connections programme[97] clearly outlines that links worker approaches should also consider the socioeconomic circumstances within which people live their lives, and attempt to address barriers to participation through support for employment, income maximisation, social security, housing, education, volunteering, etc.

Health and Social Care Partnerships should ensure they enable third sector, carer and service user representatives on Integrated Joint Boards to be adequately supported and must address previously raised concerns[98].

This should include, but not be limited to:

- Remuneration of expenses, including care, child care, and days away from paid work as required;
- Support to review relevant papers;
- Appropriate facilitation of meeting to enable every voice is heard;
- Resource and support to enable community engagement on key issues, such as service re-design or the decommissioning of services; and
- Peer learning opportunities with representatives from other HSCPs.

Health and Social Care Partnerships should also ensure inclusive opportunities for public involvement, engagement and representation beyond Integrated Joint Board meetings.

---

92 http://ihub.scot/media/2869/201701013-pas-collab-spec-v10.pdf
93 http://www.gov.scot/Resource/0050/00504535.pdf
94 http://www.gov.scot/Publications/2017/11/1343/downloads
95 https://consult.gov.scot/equality-unit/connected-scotland/
96 https://healthconnectionsmendip.org/our-model/
97 http://www.gcph.co.uk/assets/0000/6478/Building_Connections_report_final.pdf
98 http://www.parliament.scot/S5_HealthandSportCommittee/Reports/IA_report.pdf

Mental Health Service Providers

(Note: Recommendations made under this heading are relevant to all organisations providing mental health services, whether these are statutory bodies or others commissioned or grant funded by them.)

Mental health services should orient themselves towards a recovery focus, ensuring encouragement of, and support for, people with mental health issues to take up opportunities in volunteering, education and employment.

To achieve this will require tackling 'clinician's illusion'[99] and ensuring that staff acknowledge the aspirations of people lived experience to take more active roles in society. This might include secondments outwith traditional mental health services, in environments more conducive to promoting rights, relationships, and recovery.

Mental health service providers should actively promote the use of co-production in the development of services.

Providers should consider the Christie Commission report[100], which stresses co-production as an approach that enhances community empowerment. Scotland's Mental Health Strategy 2017 – 2027[101] also cites co-production as a means of ensuring that people with lived experience can be equal partners in their own care.

The 2020 Vision for Health and Social Care and the supporting Route Map to the 2020 Vision[102] highlight the importance of working with the assets which people and communities have, and of "shift[ing] the balance of power".

Education Providers

Educational settings, including nurseries, primary and secondary schools, and further and higher education institutes, should acknowledge the important role of active citizenship in supporting mental wellbeing, as well as the barriers to achieving this for people with lived experience of mental health conditions, and consider how they can enable this[103].

As 'responsible citizens' and 'effective contributors' represent half of the core capacities within the Curriculum for Excellence framework[104], settings should afford learners opportunities to put these capacities into practice regularly.

Within education, thought should be given to how student support services, support staff, and institutional policies and culture can enable civic participation. This could include:

- Supporting learners to attend societies or to take part in extra-curricular activities outside of their education setting;
- Creating more flexible approaches to academic requirements and assessment;
- Facilitating peer-to-peer and mentoring relationships; and
- Connecting students to their communities, including community-led health initiatives and advocacy projects,etc.

Public Libraries

Public libraries should facilitate mental and physical wellbeing through up-skilling staff to help people to seek relevant information and advice. This is as identified by the 'Public libraries skills strategy 2017-2030[105], and Scotland's Health Literacy Action Plan 2017-2025, Making it Easier[106].

---

[99] https://www.ncbi.nlm.nih.gov/pubmed/6334503
[100] http://www.gov.scot/resource/doc/352649/0118638.pdf
[101] http://www.gov.scot/Resource/0051/00516047.pdf
[102] http://www.gov.scot/Resource/0042/00423188.pdf
[103] http://www.gcph.co.uk/assets/0000/6278/Nurturing_Citizenship_in_the_Early_Years.pdf
[104] http://www.gov.scot/resource/doc/226155/0061245.pdf
[105] https://archive.cilip.org.uk/about/projects-reviews/public-library-skills-strategy/public-library-skills- strategy-2017-2030
[106] http://www.gov.scot/Resource/0052/00528139.pdf

This will assist to improve their:

- Sense of belong to a community;
- Education and employment prospects;
- Digital literacy; and
- Health literacy, including access to self-management resources and community assets.

Third Sector and Community Organisations

All organisations engaging volunteers should offer those with lived experience of mental health conditions the same 'reasonable adjustments' as specified in the Equality Act 2010 that they offer to their paid employees.

These might include:

- Flexible working hours (e.g. hours outside peak commuting hours);
- Access to private working space;
- Regular breaks; and
- Support provided by mentors or peer workers.

Organisations should provide peer support or buddying services (paid or voluntary) to facilitate the participation of people with lived experience of mental health conditions.

Evidence has shown that people who are provided with peer support (paid or unpaid) or buddying are more likely to be involved in community activity and to have better social networks.

In some circumstances buddying services can also be effective as initial support for involvement. This could involve, for example, showing potential new members around a building, letting them meet people one-to-one before in a big group setting, doing activities outside instead of inside,etc.

Organisations should improve their own awareness of mental health conditions and consider whether their activities are operated in an inclusive manner that would eliminate stigma and discrimination against those with lived experience of mental health conditions.

Greater mental health awareness will improve both knowledge and practice within organisations and also increase its pool of potential members. Increased involvement of people with lived experience of mental health conditions will also widen the skills base available to organisations and add an important viewpoint to its discussions.

Political Parties

Political parties should advertise their willingness to consider applications as candidates for public office from people with lived experience of mental health conditions.

Parties should offer 'reasonable adjustments' as specified in the Equality Act 2010 (see above). They should also publicly endorse and champion the provisions of the International Covenant on Civil and Political Rights, which guarantees freedom of movement, religion, thought, speech, assembly and association. We also believe political parties should recognise that the strengths developed by people with lived experience of mental health conditions can be advantageous in political roles.

Research Funders and Researchers

Research funders should support studies conducted by researchers that focus on the link between citizenship and recovery.

This should involve each person's strong connection to the '5Rs'[107] of rights, responsibilities, roles, resources and relationships that a democratic society offers to its members through public and social institutions and through 'associational life', meaning social networks and voluntary groups and activities that promote a sense of belonging to one's community and in society.

This research should further explore the barriers that prevent people taking an active part in their communities and promote solutions to overcome them.

---

[107] http://projectcitizenship.com/citizenship-mental-health/

Appendix A: The Focus Group Outline

The focus group outline was developed by peer researchers with advice from other partners. Its primary purpose was to act as a script for facilitators, ensuring that all ethical requirements were met and that all focus group discussions followed a consistent format.

Consent

Have copies of Participant Information Forms and Consent Forms available. Ensure people have a chance over coffee to chat through the information sheets and complete the consent forms, then double check they feel up to taking part today.

Explain to anyone who does not wish to consent that they cannot remain for the discussion and give them information about taking part in public life to take away.

Facilitator introduction

Welcome participants and thank them for coming.

Housekeeping and address any comfort issues (lighting/heating/seating)

Explain how long the group is expected to last and when the breaks will be. Invite people to indicate if they need an additional break and explain where they can go if they need a bit of time out.

Introduce researchers and any communication or support staff.

Outline the plan for the session and invite any further questions. Remind people that the discussion will be **audio recorded**.

Remind people about confidentiality and that they can stop if they want to. Ask the group **to respect confidentiality and not discuss what other people have said outside the group.**

Emphasise that everyone's contribution has value and you hope everyone will feel able to contribute in the way they wish. However, it is OK not to speak to every question. Facilitator will take the role of ensuring everyone has a chance to speak and ask others to **respect this in the length and number of their contributions**. Give any special instructions if communication support is being used by any group member.

Switch on and test digital recorder.

Research session: Topic Guide

- **Being involved in your community**

What does being involved in your community mean to you?

This section will gather qualitative information that was not available from the survey

Prompts:

Tell me about a time when you felt really involved/not involved? How does this affect your mental health recovery?

What are the benefits, if any, for you and those close to you? What are the downside, if any, for you and those close to you?

- **How people are currently involved**

The purpose of this and the subsequent topic areas is to amplify the survey findings and the experiences that may underlie them and explore any specific questions that arise from the analysis, such as why certain groups of respondents hold a view different from the majority.

For each subsequent topic area introduce key finding from the survey that we wish to explore further. (For example, in the survey we found that 30% of people who responded wanted some further involvement but 70% did not).

We want to hear what you think about the current level of involvement of people with experience of mental health conditions in the community.

Prompts:

Does this finding surprise you?

Does it reflect your own experience or not?
What do you think explains/lies behind it?
Should we aim to change it or not?

- **The roles that people aspire to**

Next, we want to consider the types of involvement that people said they aspired to.

Prompts:

Is this what you would expect or not?

What roles do you personally aspire to and why?

Why do you think that … was a popular role/… was not a popular role?

Are there other forms of involvement in the community that should be considered?

- **Social media**

We are interested to hear about the advantages and disadvantages of social media as a form of involvement for people with experience of mental health conditions

Prompts:

We found that n% of respondents take part in social media campaigns. Do you think that would be the case for people in your network?

In your experience does social media make you feel more involved in public issues or not?

Do you think there are any specific advantages or disadvantages of social media as a public involvement tool for people with mental health conditions?

- **Barriers and their influence on public involvement**

Looking at/hearing what respondents said were the strongest and least strong influences preventing them from increasing their involvement in public life, what are your reflections?

Prompts:

Tell us more about your experience of barriers like this. How have they affected you or people you know?

Have you managed yourself to overcome any of these barriers in ways that might help others?

Do you think the barriers are different for people in different circumstances? (who in particular?)

- **Supports that help**

The main supports that people said would help were.... In your experience, how would these make a difference?

Prompts:

Is such support currently available?

What helps/stops it being accessible to those who could benefit from it?

- **Solutions**

We have looked at the evidence of people's involvement in public life and also reviewed what prevents greater involvement. Now we want to know what you think would most make a difference and enable more people with mental health conditions to have the level of involvement in public life that they would wish.

Prompts:

What can people in mental health networks do to make a difference?

How could other social networks (family, friends, others) and the wider disability movement support greater public involvement by people with mental health conditions?

What needs to happen to change expectations in society at large?

Should services, support agencies and public organisations be doing more/something different? What is this?

Are there changes you would like to see in policy to achieve this?

- **Conclusion**

What message would you like to give to:

People thinking of getting more involved in their community?

Policymakers and anyone who could make a difference to the opportunities and support available for people who experience mental health problems to take part in public life?

Facilitator close

Thank everyone for attending and contributing.

Say that they will receive a copy of the research report. Remind them that real names will not be used.

Offer opportunity for anyone who wishes to debrief after the session.

Ensure everyone still has a copy of the Participant Information Form with contact details in case they wish to offer feedback/have reflections or questions after the session. Provide information leaflet on local opportunities/contact for engagement or ask anyone to say if they want specific information and offer to send a relevant contact.

Ask them to complete the feedback form before leaving.

Appendix B: The Partners

VOX (Voices of Experience)

Wendy McAuslan - Development Co-ordinator

Lived Experience Research Collective

Gordon Johnston - Peer Researcher

Benjamin McElwee - Peer Researcher

Michel Syrett - Peer Researcher

Heidi Tweedie - Peer Researcher

Mental Health Foundation

Chris White - Citizenship and Participation Officer

Michael Wilson - Fundraising Manager

Centre for Health Policy, University of Strathclyde

Lisa Curtice - Senior Research Fellow

Neil Quinn - Co-Director

With thanks to everyone who completed our survey and attended our focus groups.

We also appreciate the support of colleagues from the following mental health organisations who assisted us with publicity and participation in our focus groups: Action In Mind, Acumen, HUG, Mental Health Network Greater Glasgow, Moray Wellbeing Hub, and Plus Perth and Kinross.

VOX-Voices of eXperience, c/o Mental Health Foundation
5th Floor, Merchants House, 30 George Square, Glasgow, G2 1EG
Telephone: 01415721663 Website: www.voxscotland.org.uk

VOX is a Company Limited by Guarantee No 361753
VOX is a Registered Charity in Scotland No SC040646

VOX SCOTLAND
VOICES OF EXPERIENCE

Mental Health Foundation

drill
Disability Research on Independent Living & Learning

BIG LOTTERY FUND
NATIONAL LOTTERY FUNDED

UNIVERSITY of STRATHCLYDE
INTERNATIONAL PUBLIC POLICY INSTITUTE
CENTRE FOR HEALTH POLICY

Lived Experience
Research Collective