

# Alice's report

## The Value and Importance of Independent Mental Health Service User Run Groups: What do we need in Oxfordshire?

*"But I don't want to go among mad people" Alice remarked.  
"Oh, you can't help that" said the Cat: "We're all mad here. I'm mad. You're mad."  
"How do you know I'm mad?"  
"You must be" said the Cat "or you wouldn't have come here."*

Alice in Wonderland Lewis Carroll

This project and report was supported by a grant from Healthwatch Oxfordshire. The views and recommendations are those of the participants in the research and the author of the report. Healthwatch Oxfordshire is pleased to help bring them to your attention.

**restore**  
working for mental health

Registered Charity No. 274222

**healthwatch**  
Oxfordshire

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### **Introduction by Healthwatch Oxfordshire**

Healthwatch Oxfordshire is an independent organisation, established under the Health and Care Act 2012. Like Healthwatch organisations all over England, it exists to find out about people's experiences of publicly funded health and social care, and to use that information to bring about improvements to these services in its local area. It gives the people of Oxfordshire a powerful voice in shaping decisions affecting vital services.

Healthwatch Oxfordshire sets aside £25,000 a year to fund projects which enable community groups and community based organisations to undertake small scale service evaluation projects with particular groups of services users. The aim of these studies is to gather intelligence about people's experience of care, particularly from seldom heard groups, and to produce reports which shed light on those users' experiences of services. Where appropriate, these reports contain recommendations from participants, or from the report authors, about how such services might be improved. They are also a means to celebrate examples of excellent care.

The views and opinions expressed in this report are those of the participants in the study, and of Restore (the organisation who received funding from Healthwatch Oxfordshire to produce the report). Healthwatch Oxfordshire will ensure that local providers and commissioners receive the report, and that they are alerted to the recommendations this group has made, and to the experiences the project participants describe. We will also follow up with those commissioners and providers on a regular basis, over time, in order to see what changes they make as a result. Finally we will report to the report authors, through our website, and via the local media, on actions taken by providers and commissioners to deliver the report's recommendations. Where necessary, we will also highlight that no action has been taken, in order to continue to try and improve the efficiency and effectiveness of local services for local people.

**Rachel Coney**  
**Chief Executive**

**healthwatch**  
Oxfordshire

## **Introduction by Martin Realey CEO of Restore**

This study is largely the initiative of one of our former members (a service user); Alice Hicks. It was her belief that Oxfordshire does not currently have an independent mental health service-user run group and that one is needed. Its purpose would be to offer mutual support and to help others to be involved in formal user involvement roles. Alice's experience and interest in this work made her well placed to undertake the study. Her aim has been to find out how best to establish and deliver a robust and independent group. Alice's own story can be found on page 38.

The report provides evidence drawn from working examples across the country. These demonstrate how a properly resourced user-run group could help promote meaningful service user involvement. The report makes some recommendations to both service providers and commissioners about how they might support this innovation for Oxfordshire.

## **Acknowledgements**

Many thanks to the Advisory Group: Rosemary Wilson, Steve Spiers, Jeanne Humber, Trevor Lowe, Larry Sanders, Frances Ashworth and Ann-Charlotte Timander who gave their practical support and invaluable advice.

Grateful thanks to the staff and members of Capital and NSUG for being so welcoming and inspiring and giving their time to be interviewed.

Thanks to Restore for hosting the project, to Martin Realy CEO for his support and Jeanne Humber Director of Volunteering and training for her practical and personal support.

Thanks to Dr Peter Agulnik for his wise and thoughtful comments regarding the research.

Thanks to Ian Bottomley Programme Manager Mental Health Joint Commissioning.

Thanks to Angelo Fernandes ex commissioner, now Interim Director of Service Delivery at Response, for his practical help and enthusiasm.

Thanks to Jane Hope for offering her support and invaluable insights.

Gratitude and thanks to Healthwatch Oxfordshire for funding the project and to Annie Davy for her support and invaluable practical advice.

Thanks to Benedict Leigh Strategic Commissioner Oxfordshire County Council and ex CEO Restore for his encouragement.

Many thanks to all my friends who offered their encouragement, support and insights. Special thanks to my partner Kevin and members of my family who gave their loving support and listened to my ideas throughout the project.

***“Service users can offer practical and psychological support to each other through independent organisation. (User-run groups) can be a location where users can collectively articulate their experiences and explore solutions to the problems they encounter. It provides space in which people can experiment with their voices and plan to enter into dialogue with officials [..] And it provides an easily accessible group that officials can turn to when they want to consult.” (Marian Barnes: Introduction: user movements 2012)***

## **Terminology**

**Service user:** For the purposes of this report 'service user' is taken to mean people who use or have used secondary mental health services but also people who have lived with a mental illness or mental distress.

**Lived experience (LE):** A term used to describe the experiences of people who have lived with mental health difficulties and distress.

**Expert by experience:** This describes someone who has knowledge and expertise gained from their own experiences of mental distress.

**Service User Involvement:** This is any activity where the knowledge and experience of life affected by mental health difficulties is respected, valued and drawn upon to influence and shape the work of an organisation. It refers to active participation in decision making, which influences and changes outcomes. With user involvement, service users expect to share power, control and influence and to work in partnership.

**Usual suspects:** A description of service users who are well known by staff and commissioners and are frequently called upon to contribute views from their own lived experience.

**National Service Frameworks:** Standards and service models for mental health service delivery developed in 1999. They were designed to give equal priority between mental health and other health conditions.

### **Limitations of this project.**

This has been a small study and in no way is it able to claim to cover all aspects and areas in the mental health service field in Oxfordshire. There will be things that have been missed and therefore not included, due to the limited resources and time in which the project was carried out. Despite this, I hope this project will open the way for more development of mental health service user-run groups in Oxfordshire.

All the service users named in this report have given their permission for their names to be used.

**IMPORTANT NOTE:** At the time when the field work was being conducted for this project, work on setting up the proposed Recovery College had not yet been started. However, the importance of the user involvement in its design and development that is now taking place is recognised and fully acknowledged by the researcher.

## **EXECUTIVE SUMMARY**

The aim of this report was to find out how best to set up and run a robust and independent mental health service user-run group. The report proposes a model for a user-run group that could provide access to the mental health service user voice in Oxfordshire with the additional benefit of creating a user community which fosters personal growth, and improves the quality of life of its members, through the creation of friendships and relationships and the building of self esteem, self reliance and the confidence to challenge stigma.

The research was carried out by Alice Hicks, who is an “expert by experience” and has used Oxford mental health services for 30 years. An advisory group made up of people with lived and professional experience supported her and informed the research progress throughout the project.

**This report calls for the setting up of an independent, properly resourced mental health service user-run group for Oxfordshire to provide skilled, trained and supported service users for involvement in supporting all levels of mental health commissioning and service development.**

**The report concludes that such a group would:**

- **Have a positive influence on service delivery**
- **Greatly improve the lives of its members by fostering social interactions, creating friendships and positive relationships, inspiring hope, challenging stigma, promoting personal recovery and independence and lessening the need for mental health service interventions.**

**The report describes a best practice model for such a group, based on evidence drawn from other parts of England. The key features of the group recommended here are that it should be:**

- **A properly constituted organisation in its own space**
- **Staffed by people with lived experience**
- **Funded to provide training , skills development and support to users who join it**
- **Enabled to become large enough to develop a substantial pool of service users with a variety of skills and lived experiences with whom commissioners and providers can work**
- **Independent of the provider and commissioner organisations.**

## **KEY FINDINGS:**

### **1. What user-run groups exist now or had existed in the past in Oxfordshire?**

There are several service user-run groups currently running in Oxfordshire which offer members things like self help, support, socialising, and information sharing and campaigning. There is also an online forum which provides information and has a blog for people interested in mental health issues. Several other groups have existed in the past but they were not robust and closed for a variety of reasons.

### **2. What user-run groups exist elsewhere in England?**

The research contacted ten established, funded and staffed user groups running in England. These groups offered their members mutual support, a variety of activities and mostly had user representatives and often had peer support workers. Staff spoken to at these groups stressed the importance of their staff having known lived experience. Two of these groups, which did have members who were offered training, support and supervision to take on more formal involvement activities, were visited and their staff and members interviewed. They form the blueprint for the model proposed here.

### **3. The two user groups visited and interviewed**

The two groups that were visited, Capital and the North Staffordshire User Group (NSUG), were long established, funded and staffed user-run groups, whose members were able to grow in confidence and self esteem, build relationships and friendships and give each other appropriate mutual support. They provided a pool of service users, acting as a 'hub' or centre through which genuine service user involvement could be developed and sustained, with supported and appropriately trained members who are enabled to contribute at different levels.

### **4. What is the gap in Oxfordshire?**

The new service providers in Oxfordshire, the Oxfordshire Mental Health Partnership, will be required to demonstrate that their service users are being involved at all levels of service delivery and planning. They need a mechanism to access service users who are not only experts by experience but who have a variety of different skills and levels of understanding about the services they use. To ensure these users are engaged effectively and meaningfully the Partnership will need to ensure they can provide users with appropriate skills training, supervision and ongoing support. Currently service providers and commissioners find it difficult to identify enough service users who might have the confidence, skills or interest to take on these different involvement roles, or to support and train them to enable them to engage effectively.

## **CONCLUSIONS**

This study has shown that the existing user groups do not have the brief, structure or capacity to be able to provide such service users. There is no central point or “hub”, where a wider and more varied pool of such service users, with the potential and desire to be involved, could be contacted. Too much reliance can be placed on the few well known and available service users.

By having an independent and funded user-run group, where some members are supported and appropriately trained for involvement activities, Oxfordshire commissioner and providers would have a central point of contact when they need people with lived experience for involvement activities. Such a group would be able to provide a range of service users with a variety of different experiences who have the confidence and support to take on various levels of involvement work or to represent others at meetings and consultations. It could really ensure that a wider “user voice” is clearly heard. It would also be invaluable in promoting personal recovery for its members.

## **RECOMMENDATIONS**

### **Service providers in the New Oxfordshire Mental Health partnership should:**

1. Support the setting up and running of an independent user-run group for Oxfordshire where members can be empowered and could gain a sense of ownership, belonging and agency through involvement in running their own group.
2. Acknowledge and understand that a properly resourced mental health service user-run group can:
  - Provide skilled, trained and supported service users for involvement activities and work at all levels
  - Have a positive influence on service delivery
  - Greatly improve the lives of its members by fostering social interactions, creating friendships and positive relationships, inspiring hope, challenging stigma, promoting personal recovery and independence and lessening the need for mental health service interventions.
3. Fund and help facilitate and support a conference or event for service users where the issues around user involvement and the desirability and benefits of having a user run group could be explored with a wider group of service users and professionals.
4. Ensure effective Partnership working through a joint and overarching set of policies for mental health service user involvement for Oxfordshire.

**Commissioners should:**

1. Work with service users and providers to facilitate and support the setting up of a mental health service user reference group that fits the model recommended in this report.
2. Understand the importance for Oxfordshire's service users and service providers of promoting real and meaningful mental health service user involvement, where the user voice is clearly heard and accorded its proper validity.
3. Support a service user conference or event for local service users which could explore the issues and practicalities around setting up a user-run group, further meaningful user involvement and examine how such a user group could work in collaboration with the existing user groups in Oxfordshire.

# The report

## INTRODUCTION

### A story

*Once on a clear and bright summer day in the beautiful café garden, two friends met. One friend had come into the café for lunch and the other friend for a coffee. One friend was well and cheerful. The other friend was sad and unhappy and had walked to the café from the hospital.*

*They sat at the small round table in the sunlight, one friend drinking coffee and the other friend waiting for lunch.*

*One friend looked at the other and said quietly "I am dumb. They have cut my tongue out. I can't speak. No-one can hear me"*

*The other friend sat silent for a while. Then slowly she said "But I can hear you"*

This is a true story. The friend I spoke about was a patient who had been under a section for a long time in a psychiatric hospital. When he spoke to me of being "dumb" and "not being able to speak or be heard" I was powerfully and emotionally moved and hit by his sense of having lost his voice. "No-one is listening to me. No-one can hear me."

I realised that it was time for me to start my investigation. I needed to find out how a strong and well run user-run group can really make a difference to people's lives and ensure that the user voice is really heard. I want to show that having such a group would change for the better the lives of people who use services in Oxford and make sure their views and concerns are truly heard.

I am hopeful that this small study will make a difference.

Alice Hicks 2015

## METHODOLOGY

- i. An advisory group was formed, made up of a mixture of service users and professionals involved in mental health. The group met regularly during the course of the project and there were also discussions with individual members of the group at intervals throughout the research process.
- ii. A literature search was made.
- iii. A search was carried out to find out what service user-run groups were running now or had been run in the recent past in Oxfordshire.
- iv. Current service user involvement in Oxfordshire was investigated by using informal networks and contacts:
  - Talking to current and past service users.
  - Talking to the members of the management teams of the following voluntary sector organisations: Restore, Response, Oxfordshire Mind, Connection, and the Elmore Community Support Team
  - Contacting via email the key staff at Oxford Health
  - Talking with local commissioners of mental health services.
- v. Nine user-run groups in England were identified by using information given by the National Service Users Network and were then contacted by phone and brief details of their groups recorded.
- vi. Two other successful user-run groups in Bognor Regis and Stoke-on-Trent were visited and digital recordings were made with staff and members. Focus groups were conducted with group members and recorded. The recordings were transcribed and analysed.
- vii. A report was written, drawing on all the data collected and including some of the of the researcher's reflections.

## 1. What is the Value of Service User-run groups?

### 1.1 From the literature:

The value of having service user groups is about seeing shared experience and experiential knowledge as having key contributions to make in supporting people. Service users/survivors can challenge the professional interpretations of mental “illness” and develop their own view points of their distress. They can develop a critique through experiential knowledge – truth from personal experience – and they can become involved in collective action, as part of a group and create political and social change. Survivor knowledge and appreciation of the holistic nature of the person and their experience can underpin a “liberatory” approach and response to madness and distress.

However, this survivor knowledge is liable to be ignored, marginalised or misrepresented and it must be safeguarded. Key to supporting it is the development of a wide range of user/survivor-led organisations. (Beresford 2013)

Mental health service user run groups “can emphasise self defining of their own needs, have equal power among members, respect for others and their experiences, voluntary participation and learn from each other” (Zinman 1987). In a group of people whose members share identities and had similar experiences around mental distress, everyone’s experience is a respected source of wisdom. Members of such groups said “we want to learn how to keep ourselves healthy [...] Improve our mental health on our own, [...]challenge society’s attitude toward us [...] We want to empower ourselves” (Sutherland Miller 1992)

“Service users can offer practical and psychological support to each other through independent organisation. (User-run groups) can be a location where users can collectively articulate their experiences and explore solutions to the problems they encounter. It provides space in which people can experiment with their voices and plan to enter into dialogue with officials [...]And it provides an easily accessible group that officials can turn to when they want to consult.” (Marian Barnes: *Introduction: user movements 2012*)

### 1.2 Two examples of excellent service user-run groups

- i. **The North Staffordshire User Group (NSUG)** in Stoke on Trent is a registered charity and was started by user action in 1990. It has two offices, one on an acute ward of the local Trust hospital the other in the community, and at present has about 1200 members, 10% of whom are online. They have paid staff, including a CEO and 3 outreach workers and. volunteers help do admin work. It was seen as very important to NSUG members and staff that all frontline staff have known lived experience. Members are offered social events and activities and can always drop in to the office for a chat or support.

NSUG is very much focussed on having volunteer **user representatives** but the informal peer support was also taking place. These representatives go out into the community, statutory and voluntary mental health services, and acute wards and collect users' views and concerns. The representatives have the responsibility to collate them and pass them on to professionals or feed them into meetings and consultations. The group has a constitution, member agreements and a monthly magazine called the Voice as well as flyers advertising the group. Social events are also planned for representatives and members.

Over the years, NSUG have built good relationships with the local mental health Trust and mental health professionals and feel that they play an important part in helping users "have a voice."

[www.nsug.co.uk](http://www.nsug.co.uk)

- ii. **Capital** is a user-run group in Bognor Regis and is a registered charity started in 1997 again, by user action. It has about 250 members. It sees one of its main functions as having peer support workers, both paid and voluntary, who are trained and supervised to be available to support users in both community and inpatient settings. They have recently been given money by commissioners to train peer workers to work on forensic wards.

The staff and peer workers also represent users' views at meetings and consultations. It is seen as very important that the group is led by people with lived experience and all their trustees come from the membership.

Capital has its own premises, where members can drop in for social and creative activities or to receive training. When joining the group, new members are expected to sign group agreements and there are activities they can participate in. Monthly meetings are held in different localities where users concerns and issues are collected and then passed on. Travel expenses are always paid up front as it ensures that everyone can get to meetings. It is an important part of Capital's role to enable many different users to "have a voice".

[www.capitalproject.org](http://www.capitalproject.org)

Members of both Capital and NSUG spoke of how their lives had been greatly improved by belonging to their respective groups. They had formed ongoing and supportive friendships and enjoyed social and creative activities together. "*We are all available (in a crisis). We exchange numbers between ourselves.*" Capital member.

They told me of how belonging to and feeling part of their group had really fostered their personal recovery, mainly because of the flexible and sensitive support and understanding that they had received from others. They had felt less dependence on formal mental health services and were sometimes actually kept out of hospital by being supported by group staff or other members.

*“Without Capital I wouldn’t have survived. [...] I was in the middle of a field [...] and (Clare said) right, come round to Capital and I sat at the back of the room and crying like a river [...] That was 2 years ago and now I am a trustee and I am running fund raising [...]I moved forward.”* (Capital member)  
*“(Other members) have kept me out of hospital”*. (NSUG member)

Members said that they did not feel pressurised in any way and felt accepted for who they were, just being allowed to be themselves, socialising and chatting. If they felt unwell, they could just be with others who would understand how they felt and would offer appropriate support. Also being with others who had had similar experiences had helped them to challenge the self stigma and had encouraged them to overcome it. They spoke of there being a strong sense of belonging to a community, or even “family”, where members accepted and validated each others experiences. They could see other group members as role models who inspired hope and opened up possibilities for them.

*“People see the likes of Phil as an example – they see a level of recovery and that there is hope.”*(NSUG volunteer representative).

Members were able to take on roles within the group, for example becoming a peer support worker or user representative, when they wanted to and when they felt ready and confident to do so. When taking on these roles, they felt supported and were given appropriate training and offered supervision. This helped people acquire new skills and by taking on responsibilities, gain confidence and a feeling of “giving something back”. There did seem to be an element of being able to take “safe” risks within the group.

Both groups felt that having staff and volunteers with acknowledged and known lived experience was essential to the work of their respective groups. It enabled users to feel that the NSUG and Capital staff and representatives working with them really understood what they were saying and what they had expressed would not be misrepresented.

At NSUG, all front line staff (i.e. staff working directly with service users) and most of the admin staff have lived experience and the CEO said “[...] *You need people to be open* (about their lived experience) [...] *Everyone who is outward facing has had personal experience*”. It was a similar situation at Capital where Clare said “*I feel very strongly that Capital needs to be led by people with lived experience. (Some admin staff didn’t have direct lived experience but they) have to be “tuned in”*”.

Capital sees providing informal and formal peer support as one of its chief aims, although they also collect and pass on members and other service user’s views and concerns represent these at meetings and consultations.

Both groups felt that their involvement work is invaluable and does make a difference in their local mental health arenas. A great deal of mutual trust has been built up over the years between the groups and mental health staff, service

providers and local commissioners. Recently, the CCG has funded Capital to provide some of its members to “buddy” new service user students at the recovery college.

## 1.2 What their leaders say

- i. **Phil Leese**, one of the volunteer representatives at NSUG, spoke about how he became involved with NSUG:-

Phil was on an acute ward and met a user representative from NSUG. Phil said about him:

*“I felt at ease which I didn’t with the staff. He encouraged me and [...] I joined (NSUG) and he told me about volunteer opportunities.”*

*“Then we started to go out in the hospital and getting people to come along to meetings so they could express their feelings. [...] (We) said do you want to come? Is everything alright? [...] come and tell us about it. I must admit the authorities were a bit frightened of us because they saw us as militants. [...] We started the Voice, that’s our local magazine.*

*At first it was very disorganised but then we had the funding to buy a worker. [...] and he was very good at organising. [...] He organised us into what he thought we were good at. I was sent out to lots of meetings with management [...] he sent other people out to the wards. [...] You’d be (just) one user.”(i.e. one user representative went on their own)*

Phil also told me that a worker was employed part time to deliver training on meetings, safety, and other skills that you would need to be a user representative and also training on how to speak and present yourself to others. He also worked for Mind part time as a counsellor which helped with his role for NSUG. He had had his own lived experience.

*“You need people to be open and I’ve never had any qualms about saying I’ve suffered from mental illness [...] I think (self) stigma was the worst thing. (We need to) get over it ourselves [...] and it still happens. We still get (self) stigma now. One thing I found was that (being with others who were at different stages and are more confident than him) would be very, very supportive of me. [...] People were joining us all the time [...] People were joining training courses to do rep work. [...] the group got stronger and stronger and became more involved with Combined Healthcare. They began to trust us.”*

- ii. **Lorien Barber CEO of NSUG**

During conversations with Lorien she said that she felt as if there was a real need to get interested users and professionals together for discussions but added “[...] this *MUST be a service user directed.*” It seemed very important to her that service users’ views were collected and passed on by peers, so that the service users had really been fully heard and understood and had not been interrupted while giving their views. NSUG staff were seen as collaborators, giving practical support. She said:

(you need someone who) *“speaks the language (of service users). Views must not be filtered and distorted in translation [...] There is no power imbalance if users are speaking to peers.”*

She added that she thought that NSUG did struggle with some individuals members:

*“We need to have people who are positive for our organisation but who are also responsible [...] but (we need) also to have the full spectrum and not just be selective or (have) the right squeaky clean service users. However, some people are just vile” [...] She recognised the need to engage hard to reach service users “(Our) project is funded now to try and engage and recruit young people and the BME service users.”*

She said that sometimes there is a dilemma because professionals seek the views of “acceptable” users but at the same time they are saying they are not “representative”. This is why it is important that as many as possible different user’s views are collected by the representatives.

iii. **Clare Ockwell, CEO of Capital**

Clare told me that when the group was first set up, everyone was very keen that there should be fundamental Group Agreements for all members, as it was felt important that they had to “behave”. She felt that Capital was seen as “one big family”. The agreement members signed up to was informal but aimed to keep everyone “safe”. She mentioned that there had been some manipulative users. She went on to say:

*“I feel very strongly that Capital needs to be lead by people with lived experience. People have to be “tuned in”. It is very important that Capital consults and talks to its members a lot about any consultations that are with the Trust. It’s about “bottom up”. We have regular meetings, where we report what members say. We have big discussions with members. They can choose what level they want to be involved in. Members also felt that professionals should come out to their meetings.”*

She mentioned that recently local commissioners had asked Capital to provide “buddies” who would accompany and support new user students at the recently set up Recovery college.

**More detailed information about NSUG and Capital can be found in the Appendices 2 and 3.**

#### **1.4 Summary of benefits for providers and commissioners of these models**

- Active and informed pool of service users able and willing to engage in service improvement

#### **1.5 Summary of Benefits for Service Users of user-led groups of these models**

During my interviews and focus group discussions with both Capital and NSUG members and staff, significant benefits for the service users were highlighted:

- Personal recovery
- Friendship
- Having a sense of community and belonging
- Validation.
- Challenging stigma
- Safe risk taking
- Taking on roles and responsibilities
- Less dependence on services
- Allowing time to build trust in one another
- Hope-inspiring role models
- Flexible and sensitive mutual support
- Being able to “give something back”
- Encouragement
- Acceptance
- Allowed to just “be”

#### **1.6 Other Groups contacted in England**

There were some slight differences in the set up and funding arrangements of the other nine groups contacted. (See table). One group, for example, was for users and care givers, whilst another was for people with different disabilities, some of whom had mental health issues. Nearly every group had user representatives although some did not do so much formal involvement work. All the groups offered mutual support, self help and provided interesting activities for their members. Only one of the groups said it was not a requirement for staff to have lived experience, although the other groups really stressed the importance of this.

**Table of the of other service user groups contacted**

Name of Group	Location	Date founded	No of members	Status	Funding	No. of paid staff	No. of staff with lived experience	Activities	Other Comments
Rochdale Borough Wide User Forum	Rochdale	2006 by 2 service users round coffee table	For users and carer givers In contact with about 500 members	Registered charity Now a Company	Lottery Comic Relief project Local CCG	4 full time, 1 half time: Office manager Part time book keeper and IT	Most staff do have Seen as important so they can relate to members	Peer support Volunteers Representatives Monthly open forum Various craft, social and other activities Training members	<a href="mailto:www.rbfu@org.uk">www.rbfu@org.uk</a> Newsletter Own office space Mailing list "Carer voice" wellbeing group Board of trustees Policies and procedures Ground rules
Dorset Mental Health Forum	Dorchester	1992 group wanted change	400 members	Registered charity	Lottery Funded Also other funding	Range of staff Paid peer specialists	LE not required but some staff do	Peer led groups and activities Forum for consultation/ partnership work in Dorset Peer representatives	<a href="http://www.dorsetmentalhealthforum.org.uk">www.dorsetmentalhealthforum.org.uk</a> Newsletter Office Recovery Network Recovery education centre offering training for service users
Derbyshire Voice	Ripley	2000	600 members 1000 more on face book	Registered charity and company	County council and CCG £160,000 per annum	3 staff. 2vol admin 30 reps	CEO LE Employ people with right values. Important	20 paid service user representatives. Monthly meetings Online forum Strategic meetings Many trustees LE	<a href="http://www.derbyshirevoice.co.uk/contact-us/">www.derbyshirevoice.co.uk/contact-us/</a> Newsletter Flyers Own office space Online forum

Name of Group	Location	Date founded	No of members	Status	Funding	No. of paid staff	No. of staff with lived experience	Activities	Other Comments
							as role models	Emphasis on reducing stigma	Policies procedures Mad pride project
HearUs Croydon	South Croydon	Founded 2000	600 members	Charity in 2007	Core funding CCG and local council Comic relief	Paid full and part time staff. Admin staff	All staff and trustees have LE	Bank of 50 representatives 25 paid/supported user workers Activist MH awareness Monthly user and carer forums	News letter Office rented in Mind premises SLAM pays for user reps going onto wards Strong emphasis on collecting "user voice" in community and wards <a href="http://www.hear-us.org/contact/">www.hear-us.org/contact/</a>
Wiltshire and Swindon User's Network	Semington	Founded 1991 by group of people with interest	700 members all told Also some from affiliated groups	Not for profit group	Local CCG joint working with social services college	14 staff 2 admin Outreach development team other staff	Some staff LE staff	For older, mental health, learning difficulties and physically disabled people	Forums Consultations for service users with council wellbeing strategy Membership network Office Users in Management roles News letter Recovery education centre training for service users <a href="mailto:Info.wsun@btconnect.com">Info.wsun@btconnect.com</a>

Name of Group	Location	Date founded	No of members	Status	Funding	No. of paid staff	No. of staff with lived experience	Activities	Other Comments
The Mental health Action group	Derby Member led	Started patients council 1990's Current group launched 2006	230 members Also 170 others eg carers In-patient users	Derbyshire Mind gives support	NHS funded CCG JMB £5000 for group expenses Mind pays staff salaries	2 part time co-ordinators User volunteers do admin etc Rotating chairperson	Staff having LE seen as important	Campaigning Partnership with local Trust etc Training eg police. Made DVD for bus drivers User reps Social events National conf.	Campaigning group Monthly open meetings Office space in mind Web site news letter Member's handbook Affiliated to Mind Newsletter Policies and constitution <a href="http://www.mhag.org.uk">www.mhag.org.uk</a>
Sefton Recovery Group	Liverpool	User led	350 plus members					Promoting and using WRAP/self management Social and creative activities at drop in Social action	Drop in Campaigning on social issues Promoting personal recovery for group members
Launchpad	Newcastle	Founded 1999 User led and user run	No members as such. Seen as a platform for users	Unincorporated association	CCG Local authority	1 full time Some part time sessional workers	All staff with LE	Involvement work Campaigning Creative activities Information sharing Peer support groups User reps	Network with other organisations Blog Helping in designing services Office <a href="mailto:launchpadncl@aol.com">launchpadncl@aol.com</a>

## **1.8 Key Ingredients of robust service user-run groups**

- 1) Improve the lives of members and foster personal recovery
- 2) Independent from professional mental health organisations
- 3) Offer strong mutual support for members
- 4) Frontline staff, including chief executives, have openly declared lived experience
- 5) Initiated by service user action
- 6) Funded: this could be from commissioning groups, local authorities and independent charitable sources.
- 7) Having charitable status is helpful
- 8) Office premises and base of some kind
- 9) Written constitution and member agreements
- 10) Elected trustees with lived experience
- 11) Service user representatives or peer workers who are able to collect, act upon and feed in a wide range of “unfiltered” users views.

## **2. What are some of the current service user-run groups in Oxfordshire?**

### **2.1 Two long established groups:-**

- i. The Oxford MDF bipolar disorder self help group, whose aim is to provide a place where people with lived experience of Bipolar and their care givers meet monthly to share experiences and can talk about coping strategies than enable people to live with bipolar. They are self-funded, democratically run and co-ordinated by member facilitators.
- ii. Oxford Survivors in the past had been an activist group and had members who had been consulted on the National Service Frameworks, when the idea of user involvement first started in Oxford in the 1990's. Founded in X, it had a strong committee and democratic leadership and ran a drop-in centre, when "Survivor's" representatives were well known at meetings and consultations. Due to the nature of such user-run groups, members had gradually moved or drifted away, as they recovered or felt the group was no longer able to offer them anything. Some members spoke of how they no longer felt "safe" within the group. The result was that membership started to fall, although they still run a twice weekly drop-in.

Recently Oxford Survivors has been having support and encouragement from an Oxfordshire Mind worker and the Street Revolution group who are helping them to "revitalise" themselves and keep the group going. They had an AGM on 15th November 2014 and have elected a new committee and chair person.

### **2.2 Several other relevant groups were identified:**

- iii. The Oxford Mental Health Campaigners for Change whose members hold monthly meetings where they can share information and take positive action to improve the lives of people affected with mental ill health. It is for people with lived experience of mental distress or their care givers or anyone interested in mental health issues. They meet monthly at the Beehive and are self funded and supported, although not financed, by Rethink Mental Illness. Members also keep in touch online and there are flyers advertising the group.
- iv. The Oxford OCD support group is run by a person of lived experience and has informal but structured meetings once a month where members can talk to each other in a friendly but non-judgemental way, sharing thoughts, strategies and offering mutual support.
- v. Oxford Mental Health Forum (OMHF). This is an independently run web resource aimed primarily at people living in Oxfordshire affected by mental illness and those who have an interest in mental health. It provides patients/service users, carers, family and friends of sufferers, academics/researchers, mental health professionals, and others affected by mental illness with access to a range of

online material on mental health, including news stories, articles, and information on local services and research studies. One of the aims of the forum is to also allow discussion and input for the sharing of knowledge, experiences, ideas, and views, to help inform future research and service provision. The site also contains links to a range of external resources. It is independent and not part of any other organisation but works collaboratively with others.

### **2.3 Other user-run groups that had existed in the recent past:**

**Re-energize**, a successful and popular sport, recreational and social group; **SURP** (service user reference panel) whose members were “experts by experience” and would have been expected to be represent the views of other service users, i.e. be “user representatives”, at meetings and consultations; **Moonlight** whose members provided training from the user perspective and **BOOT** “Blowing our own trumpet” an “activist” and mutual support user group which was facilitated by a paid worker with lived experience and met at Mental Health Matters.

### **2.4 What is the gap in Oxfordshire?**

- i. The two long established user-run groups currently running in Oxford, namely Oxford Survivors and the Oxford MDF bipolar disorder self help group, are mainly about offering friendship, socialisation, mutual support or self help to their members. The self funded MDF group has a good management structure and there are “rules” guiding the functioning of the group and their meetings. However, it seems that although Oxford Survivors runs drop-in sessions, their group management arrangements are fairly informal, possibly putting the acquiring of its future funding at risk.
- ii. The other user-run groups are mainly about support and self help, although one has the additional remit of campaigning and information sharing, whilst another is an online mental health information site.
- iii. Other user-run groups have existed in the past, some of them have been successful to varying degrees but they eventually had to close for a variety of reasons including: not enough clarity about the role of the group; personality clashes and tensions within and outside the group; too much reliance on the group leader, who then left the group; members not feeling safe within the group because of lack of group “rules”.
- iv. None of the groups that currently exist has the specific role of providing and supporting members for involvement or consultation work, although it may be that individual members are involved in an ad hoc way.

### **3. What was found out about Service User Involvement?**

#### **3.1 The National context**

Much has been written and researched about the value and effectiveness of patient participation or “user involvement”, where the thinking has been around exploring how experiential knowledge can be embodied in service design and research. The idea that it is important has partly come about because of the introduction of a “business model” in service provision, where there is a need for customer satisfaction surveys and feed back. At the same time, activists in the growing user movement were putting pressure on government to have “a place at the table” (Nora Jacobson In recovery 2004). Involvement was seen by them as an overtly political process with the objectives of enabling greater equality and more democratic decision making as well as securing improved services. (Marion Barnes in *Critical perspectives on user involvement 2012*).

The coalition government policy claimed to want to “put patients at the heart of the NHS and stated its aim to “champion patient and carer involvement” (DH 2100a). A recent National Service User Network report says that their vision is of a future where there is “nothing about us without us”. They believe that effective and meaningful involvement does affect all aspects of service users lives and that there is evidence that good involvement can transform people’s lives and improve mental health services. It can build resilience and change lives, where there is a genuine partnership between mental health services, professionals, service users and care givers and where they are all working towards common goals of respect, recovery, choice and control for each individual. Involvement should be regarded as a continuous process and follow a cycle of improvement and development. (The NiP 4PI National Involvement Standards 2014)

#### **3.2 Rosemary Wilson’s (an Oxfordshire service user) involvement story**

*“I have been passionate about user involvement for over 20 years. Like Alice I got involved as a mental health activist out of a strong sense of injustice. I spent long periods of time as an in-patient in the 1990’s and I was disturbed and shocked by what I witnessed and experienced. I was fortunate in that I was educated to degree level and articulate, able to hold my own with professionals and to voice my concerns, but I quickly learnt that a lone voice does not carry much weight. I could to some extent fight for better care and treatment for myself, but the shutters came down when I tried to address wider issues. As I was told, “You can’t take on a monolith like the NHS.” When I tried to advocate informally on behalf of other people who lacked the confidence or skills to make themselves heard, I came up against the much-*

*abused doctrine of confidentiality. “We can’t talk about another person” even when that person wanted me to speak on their behalf.*

*Frustrated I realised that what I needed was to become part of a wider group whose collective voice stood more chance of being listened to, but I live in North Oxfordshire and early on I realised how Oxford-centric mental health services, both statutory and voluntary, NHS and Social Care were. Voluntary Services funded by the local authority described themselves as covering Oxfordshire but were provided in the City of Oxford and the cost of travel both in time and money excluded the rest of the county. I was astonished when I found what was on offer in the City. There was a sour joke amongst both staff and patients that passports were needed north of Kidlington. After travelling to Oxford to take part in a self-advocacy course, I joined Moonlight, a small group of people in Oxford offering training from a user perspective and later I became the first volunteer advocate with acknowledged use of secondary services to work with Mental Health Matters, another Oxford voluntary organisation.*

*In December 1999 I progressed to a paid appointment as a user-trainer with Solihull Mind, a strong organisation of user-led and user-led services just south of Birmingham. I found myself for the first time with an organisation whose user involvement policy states that ‘Solihull Mind values the experience, skill and knowledge people with direct personal experience of mental distress bring to the organisation. [It] aims to give people the opportunities, skills, support and confidence to enable them to work effectively at all levels within the organisation.’*

*A part of my mental health difficulties is that I find building and sustaining relationships at any level difficult, as I have low self-esteem and little trust that others value me. This difficulty which I share with many others is why we need user groups with sufficient funding to be able to offer sustained high quality support and supervision to their members. Mental health difficulties often follow a cyclical pattern, which means that active participation is often intermittent; some people who volunteer move on into employment and are no longer available to offer support. Sometimes a person’s difficulties may mean that their participation may become disruptive and requires careful management. I have probably fallen into all these categories. How fortunate I was to find an organisation very aware of it’s obligations to manage and supervise staff and volunteers!*

*Solihull Mind has grown from small drop in services commissioned through the Mental Health Grant over 20 years ago, to an organisation with a turnover of about £350k per annum drawn from a wide variety of funders including Big Lottery and Comic Relief funding. Some services are funded by the local CCG, but overall the organisation draws more funding for mental health provision into the Borough. The building (a pair of semi-detached houses) was sold to the organisation at a notional price by mental health*

*services early on and the Site (the horticultural, environmental and sports activities ground) is let by the Metropolitan Council at a peppercorn rent. The different sources of funding allow the organisation to maintain its own ethos and independence from statutory services.*

*My role at Solihull Mind grew so that apart from training, I taught social workers at Birmingham and Warwick Universities and I was employed by CHI (Commission for Health improvement), now the CQC (Care Quality Commission) as a service user reviewer of mental health trusts, gathering the views of patients and also interviewing staff alongside peer reviewers drawn from mental health professionals. We found that patients felt more able to talk to us as their peers and useful (and sometimes highly disturbing) information was recorded. For eight years I was part of Shift (a government-funded initiative working to challenge stigma and discrimination) where I [wo]manned stands and made presentations at national conferences, as well as helping to develop national policy around social inclusion and employment.*

*Since retirement I continue to work with a small group of West Midland users and carers who contribute to the education of trainee psychiatrists, working with them to develop their interviewing techniques and offering insights from the user perspective. These sessions are well-received and valued and help to give the course a high reputation.*

*By mentioning these activities I am trying to indicate what people who use services can achieve if they are given the right support and encouragement. My activities (and others reflect the same views) in Oxfordshire have been singularly unsuccessful, partly I think because mental health services have lacked any commitment to user involvement. Where I have been involved it has most often been notional/inappropriate: superficial involvement in interviewing, for example, where we were invited to talk to candidates but our views did not contribute to the selection, or a trust user and carer groups where the matters we raised did not result in any change. Probably my worst experience was working on my home ward as a user representative for a few months, only to find myself excluded from admission to the ward when I needed it.*

*I have learnt the hard way that user involvement sometimes comes at a high personal cost, both in terms of my health and in the perhaps unwittingly stigmatising attitudes of others. I have needed a lot of encouragement, support and supervision from fellow activists with direct experience of mental health issues to achieve what success I have had. As I have indicated this came professionally from a strong user organisation in Solihull and nationally through the group peer support, but in Oxfordshire I have been dependent on mutual informal support from one good friend.”*

### **3.3 Current picture of Service User involvement in Oxfordshire**

It was found that mental health professionals knew that “user involvement” in service provision and planning is now a requirement and were well aware of its value and how it could be done successfully. However, at the moment there did not seem to be clear mechanisms and procedures for doing this consistently well in Oxfordshire.

The voluntary sector and Oxford Health are involving their service users in a variety of ways, where they are asked to comment on existing or proposed service provision. However, when a specific piece of involvement work or participation in a consultation process is required, it often ends up with the “usual suspects” being asked, often at short notice. Although such service users do offer valuable insights, there is a real and pressing need to have the input from a much wider range of service users.

Service users have been invited to meetings only to realise that they were not able to contribute much to the discussion because the topic was not familiar to them or they did not feel confident or supported enough to give their views. Sometimes users were expected to read tabled papers, when they had not been given enough background information prior to the meeting and again felt unable to make useful and informed comments.

*“At a recent meeting we (a group of service users, care givers and various mental health professionals) were expected to comment on some very “dense” but important policy papers, which we hadn’t been able to read properly before the meeting. We whisked through the documents and didn’t have much time to comment on anything properly. Sometimes it feels like we are only being asked to be involved because it is a requirement and it becomes a “tick box” exercise.” (Oxford Service user)*

Service users said that involvement can feel frustrating and tokenistic and leave them wondering whether they are really being valued or taken seriously. It can end up taking an emotional toll on people and leave them feeling distressed and unwell. This can happen especially when they are commenting on services they are currently using or when proposed cuts to their services are being discussed.

### **3.4 Service Providers in Oxfordshire**

The managers of Restore, Response, Oxfordshire Mind, Connections, members of the Elmore management team, other mental health service providers and several senior members of staff at Oxford Health said they thought that “user involvement” was really important and it was being actively promoted within their services. This involvement seemed to be mostly about service users evaluating existing services or commenting on proposed new ones.

- i. *Oxford Health*: has recently set up Adult mental health Service-User forums where service users and clinicians can talk about how to service delivery can be improved. Patients from the acute wards are encouraged to attend. The forums are facilitated by staff and are usually held at Hospital or voluntary sector sites at different localities in the county. There are also Patients councils on the forensic wards. Some examples of where service users had been involved in discussions around a planned new service had proved to be really productive and informative.
- ii. *Oxfordshire Mind*: involves their service users in a variety of ways, including staff recruitment and evaluation of their services and 34% of all their staff currently or in the past have used mental health services\*. Some of their Trustees are or have been service users. They have two paid peer support staff, with lived experience, who train the peer supporters to facilitate and run peer support groups. These groups run on Monday to Friday in different locations across the county and provide a safe space and mutual support.
- iii. *Restore*: services now have successfully running members' councils which have brought about changes within the organisation. The feedback from them is reviewed at the Executive Group meetings and responses and suggestions are fed back to the council. The feedback is fed back to the Executive Group and shared at Trustee meetings. Members are also being encouraged to become Trustees.
- iv. *Response*: residents are invited to monthly meetings run by staff where they can express their views and concerns. There are weekly meetings within households for residents
- v. *Elmore team*: members of the management team told me that they have a lead worker who is responsible for user involvement. They were "evolving" a client's forum and were telling them that "It's your agenda". They felt that there was a good case for having a user group in Oxford and that It could possibly work in partnership with the Elmore team, feeding in client's comments constructively to the New Partnership board. They added that "maybe it could campaign for the disadvantaged."
- vi. There are other organisations who are involving their service users in a variety of ways. *Brookes and Ruskin* Colleges have a "Voices of Experience" group of service users and care givers who participate in the social work student interviews and training. *The Complex Needs service* employs ex service users as STAR workers. Recently, through their own initiative, service users organized and successfully ran a campaign to save their service from funding cuts. The Institute of Clinical Psychology training department have a user and care giver committee which meets regularly and have regular and valued input into their educational courses and the student selection process.

#### 4. Some developments and challenges around User Involvement in Oxfordshire

There have been some examples recently of good service user involvement with the Commissioners, when service users were properly facilitated, supported and given enough time for discussion and were clear about what they were expected to do.

One example of this had been in 2014 when an Advisory Group of service users and Care givers had been developed by Oxfordshire Clinical Commissioning Group (OCCG) to support and advise commissioners in what was called the Most Capable Provider Assessment (MCPA) process.

Ian Bottomley one of the commissioners said:

*“This process was designed to evaluate whether current providers of mental health services were capable of delivering a new 5 year £35M per annum outcomes based commissioned contract in Oxfordshire. The service user advisory group helped develop the Most Capable Provider Assessment process, which consisted of 2 parts, a written submission in response to a considerable number of questions, and an interview process (where the Advisory Group) had a section to ask open questions directly to the current providers in front of commissioners. In addition 2 users and 2 carers were involved in a more formal capacity in the MCPA as actual scorers of the current providers bid.*

*The feedback from users and carers was positive as it allowed meaningful enquiry and there was genuine support for the group from commissioners.*

*However in these cases there were drawbacks. There was a need to have a much larger "pool" of service users involved, as 50% of users were not able to engage throughout the process.[..], whilst these "experts by experience" were very capable of evaluating the model of care and support proffered by current providers, ....” (Ian Bottomley Commissioner)*

Although some service user involvement is valuable, it needs to be taken into consideration that being “involved” with the services that you are currently using can be prove difficult and stressful for people.

*“Probably my worst experience was working on my home ward as a user representative for a few months, only to find myself excluded from admission to the ward when I needed it.” (Rosemary Wilson current service user)*

When service users are at meetings or consultations they might not necessarily be familiar with what is being talked about or what they are expected to know. What is being discussed may not relevant to them when organisational language or jargon is used. Some service users may not feel confident or supported enough to speak out. In these cases service users may ask themselves why they are actually there. It could

be argued that some organisations are tokenistic in their approach because the 'user-involvement' box had to be ticked?

For the whole process to be meaningful, service users would need to have the appropriate support and be given the skills and background information at the required level so that they are able to meaningfully take part in any discussions or consultations. Thought needs to be given to any skills training that might be needed and for service users to be offered on-going support, and any supervision that might be required.

*"(I) would like training to be a volunteer, if (I was) called upon to do diverse stuff [...]. "Service users can get over-extended and get ill again. It affects their lives." (a current service user.)*

*[..] "experts by experience" were very capable of evaluating the model of care and support proffered by current providers, they were understandably much less confident when evaluating technical aspects such as details of finance etc.." (Ian Bottomley Commissioner)*

However, it can happen that the same service users are invited to be involved in some way, often at short notice. Maybe these "usual suspects" are asked because they are known and trusted and would have the experience and confidence to express their opinions at meetings. Though it is valuable to have input from these users, there is a real need to include a much wider range of views and experiences.

*"I was asked on Friday to go to an important consultation meeting in Aylesbury early the next Monday morning. I really would have liked to go but I couldn't get there so early from Oxford" (a service user)*

The new Oxfordshire Mental Health Partnership providers are proposing to have service users involved in many additional and perhaps more demanding ways: chairing meetings or groups, co-designing new services, facilitating training, where as well as being "experts by experience" many different levels of skills will be required. These service users will have to be reasonably well and robust and be able to cope with the more intellectually challenging and skilled work. As with anyone expected to take on this kind of work, they would need appropriate skills training and certainly ongoing support and supervision.

*"I feel that people with lived experience of mental distress in Oxfordshire could contribute far more to the development and growth of modern mental health services if money could be found to support an independent user organisation which could offer input and advice and support volunteering activities within the statutory sector at the same time as growing people's self-esteem and independence through peer support and by giving them a sense of achievement." (Rosemary Wilson current service user)*

It does seem as if current involvement of service users is usually about evaluating existing services or commenting on proposed new ones and there have been good examples of this:-

*"[...] excellent engagement of service users [...] in the design [...] of the new AMHT models.."* (Senior staff member Oxford Health)

*"The feedback from users and carers was positive as it allowed meaningful enquiry and there was genuine support for the group from commissioners".*  
(MCPA Ian Bottomley)

As has been said, user involvement can be stressful and people do need support and appropriate and suitable training to do this. A current service user said *"(I) would like training to be a volunteer, if (I was) called upon to do diverse stuff [...] Service users can get over-extended and get ill again. It affects their lives."*

**Researcher's note: Service users from Oxfordshire are now being involved in the planning and design of the proposed Recovery College.**

## **5. What is needed in Oxfordshire?**

### **5.1 The Commissioners 'view**

Ian Bottomley, Programme Manager - Mental Health and Jointly Commissioned Services, replied to the following questions:-

#### **Q. From your perspective, what do you know about current/past service user involvement in mental health services in Oxfordshire?**

*"There have been a number of user led groups (SURP etc) which have all worked best when they had some structured support, but have all tended to collapse in on themselves apparently because of internal pressures/issues within the groups. This has been unsatisfactory from all perspectives.*

*What has been much more successful has been the involvement of users in specific pieces of redesign/procurement (SIL/Keeping People well/OBC) and in forums such as BMHO and in the Hearsay and Sounding Boards events. A number of organizationally-based user groups have also existed and been effective in helping those organizations develop services and ensure that they are responding to the user voice. As commissioners we have always found it easy (often via the providers for example. Mind, or the Complex Needs Service) to go out and get the views of people who use services"*

#### **Q. What would you say is working?**

*"Task led engagement on specific topics. There is a significant group\*of "experts by experience" that commissioners can draw on to support often quite complex pieces of work. These experts are very well-connected and well-versed in the larger strategic issues and that means we get very well-informed engagement that adds to the quality of our commissioning response.*

*The proposals in the OBC contract bid (Recovery College, engagement in governance) are very promising and may be indicative of a significant shift in our main provider's approach to user engagement."*

\*Author's NOTE: From my experience the significant group Ian is referring to here consists mainly of care givers, as there are fewer service users who can be drawn upon.

#### **Q. What might be the gaps?**

*"We lack a go to voice of the users who will also (and independently) raise issues that are of concern to people on the ground. We tend to have to rely on the well-established Carer forums to act as proxies for users and (especially) report here and now issues. Carers sit on the JMG but users do not because we wanted to invite reps from the "user community" rather than "people we know". We need an equivalent of Unlimited or My Life My Choice for mental health, and although we have known that for a while we have not found an effective way of engaging with people to discuss how that might be taken forward.*

*There may be an opportunity to build on the on-line Oxford Mental Health Forum?"*

**Q. What might need to happen to improve user involvement in Oxfordshire?**

*"(Having) a group that could support user engagement in the more general sense and encourage more people to bring forward their views. Consider using different ways of developing engagement (e.g. OMHF)"*

**5.2 Mike Foster Acting deputy director of nursing at Oxford Health gave the following responses:-**

**Q. From your perspective, what do you know about current/past service user involvement in mental health services in Oxfordshire?**

*"I have had various experiences of SU groups and involvement. There used to be a trust level group as you know some years ago and I would attend that for the then director of nursing and it did help to make some changes but it was hard to get new members as I recall. Young people were very actively involved in the development of the new Highfield Unit and Boundary Brook House and the Article 12 group remains very active. In Forensic Services there are patient's councils which are well attended and do lead to changes. In adult services, there are community SU groups that relate to the new AMHTs but I have heard that attendance is varied. The wards also have community meetings, which I think are usually held about once a week. All areas undertake patient experience surveys and are expected to demonstrate that they are reviewing their services and making changes in response to this feedback. I have been involved in a number of meetings with Governors of the Trust which have included service user and carer governors – and they have also contributed to projects such as Safer Care.*

**Q. What would you say is working in Oxfordshire?**

*"Article 12 in the Children and Young people's Directorate is very active and the Directorate see them as a valuable resource and use them in a variety of ways. The older adult – I think mostly carer – group also seems actively involved with the work of the Older People's Directorate. Apart from the Patient's Council, which is well established, I think the Adult Services groups are more variable and have some way to go."*

**Q. What might be the gaps?**

*"I think that it would be useful to have a reference group at trust level, in addition to the Governors, to discuss the service developments of the Trust and how we can better embed patient experience/feedback in what we do."*

**Q. What might need to happen to improve user involvement in Oxfordshire?**

*"What has been most successful in the Children and Young People's Directorate is having a worker, full time, focussing on patient experience and involvement. This person can then support and 'train' service users to make a valuable contribution to the work of that Directorate."*

## **Q. Where do you think these suitably skilled and supported users come from?**

*“I wonder if service users can be recruited from any of the on-line and other groups that exist as well as being actively invited and supported through community and in-patient services. The third sector/ charities – such as MIND and Restore can engage with their members as well.”*

### **5.3 Notes from a discussion with Benedict Leigh Strategic Commissioner Oxfordshire County Council**

Benedict acknowledged that user run groups can promote personal empowerment, growth and recovery and help combat stigma and that members could have an understanding of their own identity. He felt that being independent was important. However, he said that such a group would have to offer something that would transform services much as the introduction of the concept of recovery into services had done. We discussed what that new transformation might be, as he thought that the commissioners would be interested in supporting a service user-run group that might be instrumental in transforming and changing services for the better.

**5.4 Angelo Fernandes (ex commissioner, now Interim Director of Service Delivery at Response)** *“Having engaged and consulted with service users as part of my commissioning work, I consider the development of a service-user led group the natural next step to ensure that an empowered and assertive service user voice in relation to mental health commissioning is ensured in Oxfordshire. If set up and run effectively, such a group can be of real help to commissioners to ensure that world class mental health services are developed which radically improve experience and outcomes for users and carers.”*

### **5.5 What the Service Users want**

I was able to talk to a number of local service users. They all expressed an interest in having a user-run group in Oxford and said things like *“I’m up for that!” “That’s what we need!” “YES! A place run by us so we can be ourselves and talk freely. Not have to agree with how things are”. “Have a place that we were running ourselves. Where we could be ourselves and do things that we wanted to. No pressure though”* A service-user volunteer said *“We need to have some action! Nothing really happens here (at a voluntary centre). We want to be free to express ourselves and plan things, do things. Activism! Be our own people”*

Another user said *“My mental health centre closed and now I can’t find anywhere to go that is supportive but also has interesting activities. I miss the companionship the group offered. I don’t always feel very well. I don’t want to be dragooned into joining classes and workshops or pressured into getting back to work.”*

A patient on a ward said *“We need a place of our own where we are understood and listened to. Where we feel free. What about a café? I would love to help you design the place and chose the colours”*

A worker with lived experience said that he felt having a user-run group in Oxford was valuable and could be a place where “*oppressed or people beaten down by the system could come together and just be allowed to “be” and share their ideas.*”

Rosemary Wilson said:

*“A part of my mental health difficulties is that I find building and sustaining relationships at any level difficult, as I have low self-esteem and little trust that others value me. This difficulty that I share with many others is why we need user groups with sufficient funding to be able to offer sustained high quality support and supervision to their members. Mental health difficulties often follow a cyclical pattern, which means that active participation is often intermittent; some people who volunteer move on into employment and are no longer available to offer support. Sometimes a person’s difficulties may mean that their participation may become disruptive and requires careful management.”*

## **5.6 Summary of what was found**

- There is no current independent user-run group that can provide some of its members, who would be supported, trained and supervised, to do involvement work
- There is no funded, independent and robust mental health service user-run group that can offer mutual support and understanding, empowers and genuinely improves the quality of life of its members
- There is no mental health service user reference group, which is made up of users who could collect a wide range of other service users views and represent these views at meetings and consultations and feedback information about any decisions made
- There is not enough input and involvement from a wide variety of different service users, resulting in too much reliance being made on a few users who are known as the “usual suspects”.
- There is no central “Hub”/centre or group which professionals, service providers and commissioners could contact to provide them with a number of supported and appropriately trained service users for involvement work
- There is no joined up or overarching policy around mental health service user involvement in Oxfordshire.

## 6. Conclusions

In late 2014 the **“New Oxfordshire Mental Health partnership”**, which was brought together through outcome based commissioning, proposed to involve service users in many ways. They will need to be not only “experts by experience” but also have a variety of different skills and levels of understanding. For this involvement to be meaningful and effective these service users will need appropriate skills training, peer support and supervision.

Currently mental health service providers in Oxfordshire, both statutory and voluntary, do involve their service users in a variety of ways, including patient’s councils and forums, patient/client “satisfaction” surveys and questionnaires and peer support projects. Some service users may also be involved in an ad hoc way in decision-making consultations, staff training or meetings and so on. However, at present there is no central point where contact can be made with a “pool” or number of service users with the variety of experience and appropriate skills and who have the confidence to undertake the required involvement work.

The robust, independent, funded and staffed user-run groups looked at in this study showed that their members were enabled and empowered to successfully partake in involvement activities. Members of these groups had been given appropriate support and their involvement proved a positive experience for them and local service providers. It had also impacted on members’ personal recovery and had fostered a real sense of their being able to “give something back”. It was found that these groups had the capacity to provide on-going support and training to members wishing to be involved, proving the group to be a really useful resource for service providers and commissioners in the area.

During conducting this study, it was also found that people with mental health difficulties can suffer from low self esteem and may not always be able to sustain relationships or feel valued by others. Due to the nature of mental illness, service users’ ability to participate can be intermittent or their behaviour may become disruptive because of their distress. Furthermore this study demonstrates how a user-run group can, by creating interdependent friendships and relationships which in turn help to build self-esteem and self-reliance, also give service users the confidence to challenge stigma and the self-stigma that emanates from mental distress.

Importantly, this study demonstrates the role user-run groups can play in reducing dependence on mental health services, by providing empathetic and understanding service user communities, where being with others who have had similar experiences of mental distress, can provide sensitive support and encouragement, foster personal growth and improve the quality of their lives.

This study is able to clearly show the huge benefits for Oxfordshire service users, service providers and the commissioners of having a robust, funded, independent and well run service user-run group.

## **7. RECOMMENDATIONS**

### **Service providers in the New Oxfordshire Mental Health partnership should:**

1. Support the setting up and running of an independent user-run group in Oxfordshire where members can be empowered and could gain a sense of ownership, belonging and agency through involvement in running their own group.
2. Acknowledge and understand that a properly resourced mental health service user-run group can:
  - Provide skilled, trained and supported service users for involvement work at all levels
  - Have a positive influence on service delivery
  - Foster social interactions, create friendships and positive relationships inspire hope, challenge stigma, promote personal recovery and lessen the need for mental health service use for its members
  - Promote independence and sense of agency and belonging for members
3. Ensure effective Partnership working through a joint and overarching set of policies for mental health service user involvement in Oxfordshire.

### **Commissioners should:**

1. Work with service users and providers to facilitate and support the setting up a mental health service user reference group where members can be empowered and could gain a sense of ownership, belonging and agency through involvement in running their own group.
2. Understand the importance for Oxfordshire's service users and service providers of promoting real and "meaningful" mental health service user involvement, where the user voice is clearly heard and accorded its proper validity.
3. Enable and support the running of a user friendly and organised conference or event inviting local service users and members and staff of Capital and NSUG, where the issues around the benefits and desirability of having a user-run group can be fully explored.

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## **APPENDIX 1**

### **1. The Researcher's Story**

My story begins in Oxford where I was born in 1943. I then spent my first two years of my life in war-torn London where my parents lived. I was nearly blown up in my mother's arms by a doodle bug. Years later my life was blown apart for a very different reason.

When I was two and a half, I was sent to boarding school. Being suddenly apart from both my parents at such a young age was very traumatic and has had long term consequences for me.

I guess the part of my story that is really relevant to my research project started in the summer of 1983, when I was admitted to an acute ward of the Warneford hospital, with what was described in my notes as "a florid mania". I was also being Alice Christ! I wasn't aware of this at the time but this was a water-shed moment in my life, a massive change of direction – I had taken the path less travelled. My "psychiatric career" had begun. I had entered the world of the MAD!

The following years were ones of enormous struggle and pain for me but with moments of wonderful fantasy and extreme happiness, feeling so close to God and connected to all creation. I was experiencing wild mood swings, happening twice during each year and I spent a lot of time going in and out of hospital. The mental health professionals gave me a diagnosis of Manic Depression. My daughter called me a "manic impressionist" as if I belonged to some interesting school of artists or poets.

My life during the 80's and 90's was one of struggle and difficulty and pain, with my moods swinging from creative elation to crippling lows. Who was I? What was I? I felt I had no worth or value.

Slowly, small step by small step, I began to heal. My life gradually began to rebuild. I got back a sense of belonging and being of worth. I found a new sense of identity other than that of a manic depressive and patient. Many people and events helped me - my unconditionally loving mother and step father, my children and friends, really supportive mental health professionals and meeting so many other fellow travellers on my journey.

In the mid 1990's I became aware of the user movement. I became an activist and campaigner. I joined a service user organisation called Oxford Survivors and Moonlight, service user a training group. I went to those formal meetings where we were consulted about the National Service Frameworks. I vividly remember those early meetings and consultations. They were often rowdy, difficult and confused, as no-one then quite knew how to "be" with us. But they were "real" and dynamic, with lively face to face discussions and exchanges of ideas. The chief executive, the director of nursing and staff of the Mental Health Trust were all there. I desperately

wanted to make the world aware of how we struggled and survived. I wanted to challenge the myths and fear that surrounded “madness”. I wanted to do things that would show how people like me could live and thrive despite having a serious “mental illness.”

I have met many, many fellow travellers on my crazy journey - so many interesting, highly intelligent and courageous people, often struggling with their own pain and distress but able to offer friendship as well as compassion and kindness to me. Further along the trail on my long recovery journey I became involved in research and have worked for the Royal College of Nursing, Thames Valley University and Rethink Mental Illness as a “user” researcher. But as a researcher and trainer I have never lost sight of the fact that I will always be that person who has had years of experience of the anguish and tears of mental distress! This is part of who I am and I am proud of that. I care deeply for my fellows, the people who live and survive like me. I am passionately committed to promoting a better understanding of madness and want to do something that can make a difference for the better in our lives.

Alice Hicks 2015

## **Appendix 2. The North Staffordshire User group (NSUG)**

(NSUG) covers North Staffordshire and Stoke on Trent and is a registered charity which receives its funding from the local CCG and various charities including some local authorities.

It was started in 1994 by a small group of service users who were unhappy with the mental health services they were receiving at the time they managed to get government funding and were able to rent an office with initially 3 members of staff. It now has 2 offices one in Hanley and another based in the local psychiatric hospital and at present has around 1200 members, 10% of whom are online. They now employ 7 members of staff which includes their chief executive and have a number of volunteers. It is seen as very important to NSUG members that all frontline staff have known lived experience of mental health.

The group has a constitution, and is lead by Trustees who have to be members and are elected annually at its AGM. They also produce a magazine called the Voice which goes out 4 times a year and a local voice that goes out 3 times a year to all the members. They also hold a number of member's forums in a variety of locations where speakers come along to talk about mental health services, benefits etc. and they also use these to carry out consultations on things like proposed changes to services. They produce a number of leaflets in house around mental health topics which volunteers help to photo copy. Over the years, NSUG have built good relationships with the local mental health Trust and mental health professionals and feel that they play an important part in helping users "have a voice."

**[www.nsug.co.uk](http://www.nsug.co.uk)**

*"Everyone who is outward facing has had personal experience"* CEO NSUG

So do its Trustees, who are elected for a years term of office from the membership. They have two offices, one of them being in the local Trust hospital, the other being at the Dudson Centre which has a variety of voluntary sector organisations based there giving them the opportunity to work collaboratively with their staff.

NSUG holds User forums every 2 month as they feel that it is very important that "everybody has a voice" However, they can be a struggle to get attendance. *"People are reluctant to travel and some of it is illness. So it is a perpetual problem"* CEO NSUG. They find that meetings are more successful if issue based for example the closure of a ward or have an invited speaker.

### **The Role of NSUG**

New members have to sign a sheet with contact details, as staff would need to know who to contact if someone became unwell. However, no records of medical conditions are kept. Anyone who wants to be in a volunteer role would be expected to have some training, which would be about general mental health awareness but members wishing to become user representatives receive special training. Members can always drop in to NSUG for mutual support or have a chat and socialise. They described a sense of connection with each other and the co-

ordinators. *"You can pick up the phone and talk to (NSUG) staff for a chat" People can ring office and get support.*" (NSUG Representative)  
Some of the members volunteer in the office, helping with admin or working on the Magazine.

### **User Representatives**

NSUG sees a big part of its role, apart from the mutual support that members give each other, as having voluntary user representatives, who are mostly generated through the membership. There are also paid user representative Co-ordinators whose role is to organise training and give supervision to the volunteers. Each user representative would receive skills and confidence training for their role and are CRB checked. Each volunteer signs an agreement which includes what is expected of them and what support they can expect to get from NSUG. Every representative volunteer would have their own named supervisor with whom they are expected to keep in touch and flag up if they are experiencing any difficulties. The co-ordinator would be aware if the volunteer was doing too much and would advise that they take a break from the work. Another important role of the co-ordinator is to be aware that when a prospective volunteer is not quite suitable to be a representative, they would need to be tactfully told and then perhaps offered some other job in the office.

*"You need to be the right person doing the right job and its sometimes not best for them. And we have to tell them this"* (NSUG Volunteer co-ordinator)

The role of the representatives is to go onto the wards, out into the community and any mental health drop-in or services and collect and record user's view and concerns pass them on to the representative co-ordinator.

Lorien CEO of NSUG said: *"(User representatives are) absolutely about that face to face contact Getting them (service users) to talk to you about the issues, **actually hearing them, validating** their experience and recording it. (its) about having daily contact with people currently in the services and talking to them about their current experience and recording that. We have always steered towards secondary care. (Services users) where people are really unwell and really vulnerable if they are unable to express their experiences our staff and user reps can do it for them. Representation is to ensure we are there to represent those who haven't much support and are not able to speak up for themselves."*

She expressed a concern about formalised peer support *"Has it become to formulated and rigid. But of course peer supporters do need to have some structure or it can become weak or flabby. People do need to have the right skills and training"*

Representatives go out to mental health organisations, both statutory and voluntary, in different geographical areas and always in pairs. They have regular supervision, every two months although they would be given more if the co-ordinator is concerned about them becoming over-worked or unwell.

The Volunteer co-ordinator said *"We always ask them (the rep volunteer) to show they are feeling. We always keep in touch if they are taking some time out and when they feel ready to come back suggest they do it slowly. (Recently) a meeting the representative was going to was causing him some issues, so he stopped going."*

She said that they can always ring staff at the office if they concerned about a service user they have talked to *"I wouldn't just fill in a report. I would ring (the co-ordinator or other member of staff in the office) and say I'm worried about someone. They would then either ring the service user or contact their support worker at the centre and say we are worried about someone"*.

It is a requirement that the volunteer representatives pass on their collected and collated user issues and concerns to the co-ordinators, who would then pass them on to ward staff or into meetings and consultations. One of the co-ordinators told me that she felt that it was important that positive comments are reported too. *"(We) must be clear about what service users find really valuable."* (NSUG volunteer Co-ordinator)

#### **How effective is NSUG?**

The CEO said that NSUG had a good reputation within the local mental health arena and that a real sense of mutual trust has been built up over the years between NSUG and mental health staff and organisations. *"[...] Staff are really supportive of NSUG. It's all about positive personal relationships."* However, she said NSUG staff have *"to be careful not to be seen as too much on the mental health staff's side."*

When the representative go onto the wards and ask questions about the situation on the ward they are visiting, they would expect staff to answer their questions honestly. One representative said *"I know all the staff and I trust that staff of that unit."*

#### **How does NSUG find new members?**

NSUG members stressed the importance of talking to people face to face when finding new members. The representatives go out everywhere in the community and drop-ins and encourage people to join the group. They distribute flyers and leaflets and advertise in their magazine and on their web site.

Some of the members I talked to said that they thought that they should become more activist and start campaigning again. *"Maybe we have lost that campaigning element now we need to get it back again!"* NSUG member

Some of the members I talked to expressed the view that maybe they should become more activist and start campaigning again. *"Maybe we have lost that campaigning element now [...] we need to get it back again!"* NSUG member

## Appendix 3. CAPITAL

### The organisation

Capital was founded 1997 by service user action and was initially funded by Social Services “slippage” money. It now receives its income from the local commissioning body and fund raising by group members. Several “high profile” service users, including Jim Read, Thurston Bassett and Anne Beales, were enthusiastically involved in setting it up and the present CEO Clare Ockwell was one of the founder members. Anne (who continued to support Capital until 2005) worked from her car, which had become her office. Everybody found new members by going out and talking to all sorts of people and service users. *“We all did a lot of leg work”* CEO Capital.

It was thought to be very important right from the start that group agreements for members were developed and put in place to make sure it was safe place and that *“people behaved themselves”*. When people joined the group, there were things that they could do right away and a diary of events was created for new members. Now taster courses and events are put on for new and current members and general mental health awareness training is offered when people join Capital.

Membership now covers whole of West Sussex and is now about 250 people. In 2000 Capital became constituted charity, whose trustees are now mostly former members, all of whom have lived experience.

Many documents have been developed by the group over the years for example health and safety, and confidentiality policies. Volunteers and peer workers are especially required to strictly adhere to confidentiality in their work. Clare and I discussed would happen if some members were causing difficulties or what not suitable to be volunteers. She told me that if members were *“difficult”* or *“dangerous”* they would be asked to leave the group.

One of the vital things about Capital that was picked up during conversations with the Clare, the CEO of Capital, was the importance of their **staff having acknowledged and known lived experience**. *“(Having staff with lived experience) gives you an authority when coming up against the bad attitudes and prejudice (of MH professionals). It can help challenge stigma”* (One of the office staff).

*“There is nobody in Capital that does not have lived experience”* a member said. The Clare said that staff would be expected to disclose their MH experiences. *“We have to disclose ours don’t we?”* She said that one member of the Northern locality staff admitted that she had only had **some** personal experiences but that this woman was *“very tuned in”*. The public generally know that Capital staff have lived experience and she thinks that helps challenge the stigma and myths around mental health.

*“I think its very important for people especially the public to know that a person who is suffering from mental health (..) is not stupid.”* A Capital member

### **What Capital does**

One of Capital's main functions is to provide formal and informal peer supporters, who are given training, support and supervision. *"We run our own accredited courses for them."* said Clare. They also have Petal training, which is delivered by a local university. Some of these peer volunteers go onto the acute wards and facilitate the Patient's View point meetings, where they listen to patient's concerns and views. These are written down and passed on, anonymously unless the patient wants their name mentioned, for action would be taken to address them.

*"(On the ward when talking to patients) it is important that no staff are present. Notes of what is discussed are sent to the Modern Matron for her/him to action any points that need to be." CEO of Capital*

At the moment some peer supporters are paid and are on Capital's pay role but as yet there is not quite enough for them to have steady or regular work. Recently Capital has been given more funding to train extra peer workers, some of whom will go onto the forensic ward. Recently Capital has been received funding to send some peer "buddies" for new students at the local Recovery College. A few members do paid do consultancy work for the local Trust.

Clare mentioned that some members don't want face to face contact, so they could be contacted by phone if they are happy to give their number. Other members exchange numbers, so they can contact each other if they wanted a chat or needed support.

Volunteers can have various roles in Capital e.g. office work, peer support, running groups, fund raising etc. New volunteers are be able to shadow more experienced ones so they can understand the role and gain confidence. There is an understanding that people are sometimes not always well enough at that time and then another member would *"Step into their shoes"*.

They are rewarded for their work by social events being arranged for them and having "cakes"! Clare feels that it is very important that **Taxi and bus fares are paid upfront**, as it supports and encourages members to come to meetings and that is "socially inclusive".

Capital has weekly drop-ins, where members can have coffee and friendship. Some days there are activity groups such as art and photography, often led by other members. Members can participate in activities or volunteer for various roles when they feel ready and able to but no-one is under any pressure to join in if they don't want to. Members are able to develop at their own pace. One member told me about herself. She said she had been encouraged to come to Capital, having not been able to go outside for some time. At first she just watched the art group but slowly, as she gained confidence, she started to join in. Now and uses her artistic skills to lead the art group.

New members can attend a 12 sessions training course for new members which would include general mental health knowledge, what is expected from members of the group etc. Although this is not compulsory, new members are encouraged to attend.

Member's meetings are held once a month in all localities facilitated by paid Capital staff and Capital staff organise an Annual "taster" event to encourage new members (60 people attended the last event)

*"I feel it is important that we (Capital) consult and talk to our members a lot about any consultations that are having with the Trust. It's about "bottom up". We have regular meetings (in different localities). We report (back) what our members say. We have big discussions with our members. They can choose what level they want to be involved in. We send out emails and sometimes letters. [...] Commissioners want feedback from members. I make sure they go "warts and all". I do not edit them"* (Clare CEO of Capital)

The group prints a Newsletter which lets members know what is going on but also informs prospective members about the group and any volunteering opportunities. It holds **Patient's View Point** meetings on the wards where members go and talk to patients without staff present. Any concerns that they might have are passed anonymously to Modern Matrons. Volunteers go out and about in the community and talk to people and put leaflets and flyers on wards and public places to advertise what Capital does. Some volunteers work in local organisations for example CAB. They often put on fund raising and promotional events in the community to spread the word about their work and attract new members.

### **What the members get from belonging to Capital**

*"Members get a great deal out of being involved in Capital. It's OK to be who you are"* (CEO of Capital)

The members told me how you could join Capital. *"It's easy to join. Just sign a form. (You can) drop in for a coffee once a week or go to one of the activity workshops."* They spoke about how close and strong friendships had been built within the group and how a sense of understanding and empathy exists between members. *"Members are non judgemental of each other. We watch out for each other"* They all expressed how a strong "sense of belonging" to their group was very important to them. At Capital you were allowed to be yourself, as other members would understand your mood and that maybe sometimes you were just allowed to feel ill. A member told me *"You are very comfortable. That is the point. (Coming to the group would) makes you feel up-lifted"* Another very powerful thing was about by having the support of other members of Capital had helped keep you stay out of hospital *"Without Capital I wouldn't have survived. [...] I was in the middle of a field [...] and (Clare said) right, come round to Capital and I sat at the back of the room and crying like a river[...] That was 2 years ago and now I am a trustee and I am running fund raising [...]I moved forward."* Capital member

Capital organises “user friendly” events for members, where quiet rooms would also be available. Clare said it was very important that people were able to get to discussions, meetings and events and taxis would be provided for people who couldn’t get there by public transport. Sometimes other members would collect and support people to get to meetings if necessary. Lastly and most importantly members told me that they set great store by the fact that they can have FUN and enjoy each others company and friendship. They spoke of laughter and jokes and their own “black humour”.

### **Does Capital make a difference to the local MH arena?**

Members talked of how they were kept out of hospital with the real support and understanding of what was needed in crisis situations being given by fellow members. They discussed how it could save commissioners money by members not having to use formal MH services so much and of how fellow members were able to respond in an immediate practical way that perhaps mental health professionals couldn’t always do.

*“What is the least expensive way [...] of dealing with folk with mental health problems? [...] (They go) in and out of hospital, (and) the cost of keeping someone in hospital [...] is absolutely horrendous [...] and if you keep them out in the community and they are helped by groups like Capital [...] The funding for Capital [...] isn’t 10% of what you are paying for somebody in hospital” (Capital member Ex MH nurse).*

They felt that good relationships of trust and respect have been built up with the commissioners and mental health staff and professionals within the local Trust and voluntary sectors.

*“(Capital’s work) is appreciated by those we actually help and we know that from face to face (interactions). It is appreciated by hospitals and the modern matrons. [...] There is mutual aid for Capital members themselves [...] We practice outreach into the communities, to outside (ie people who are not) Capital members. [...] There is quite substantial anecdotal evidence from our partners ie commissioners, health (organisations) etc that capital makes a hell of a difference” (Member ex MH Nurse)*

However, Clare told me that it is still sometimes still a struggle to get professionals to see the point and real importance of the work Capital is doing. In the past, a member of Mind, who was supporting Capital, argued strongly against paying travel expenses for members to go to meetings. Clare had had a battle to persuade her why she felt that this was really important, as it ensured that people got to meetings. Also Clare described a recent meeting of a local charity when she felt “shouted down” by other members of the panel she was on. However, she concluded by saying that now the local CCG is now directly funding more of Capital’s members to become peer volunteers, which she said really acknowledged the importance of their work at Capital. She really feels that Capital is really having an influence for the better in the area and is certainly improving the lives of its members.

