Helping Self Help

FINAL REPORT

May 2017

HVA
Hastings Voluntary Action

RVA
rother voluntary action
innovating : changing : influencing

NHS
Hastings and Rother
Clinical Commissioning Group

Helping Self Help

We would like to thank the **Hastings and Rother Clinical Commissioning Group** for providing the resources for this one year project, the commissioners from **East Sussex County Council** who helped shape the delivery of the project, the project team members from **Hastings Voluntary Action (HVA)** and **Rother Voluntary Action (RVA)** who delivered the work (the voluntary and community sector infrastructure organisations for Hastings and Rother), but most of all to the members of the voluntary sector who generously gave up their time to help develop better support and communication channels and lay the foundation for stronger relationships with the formal health economy.
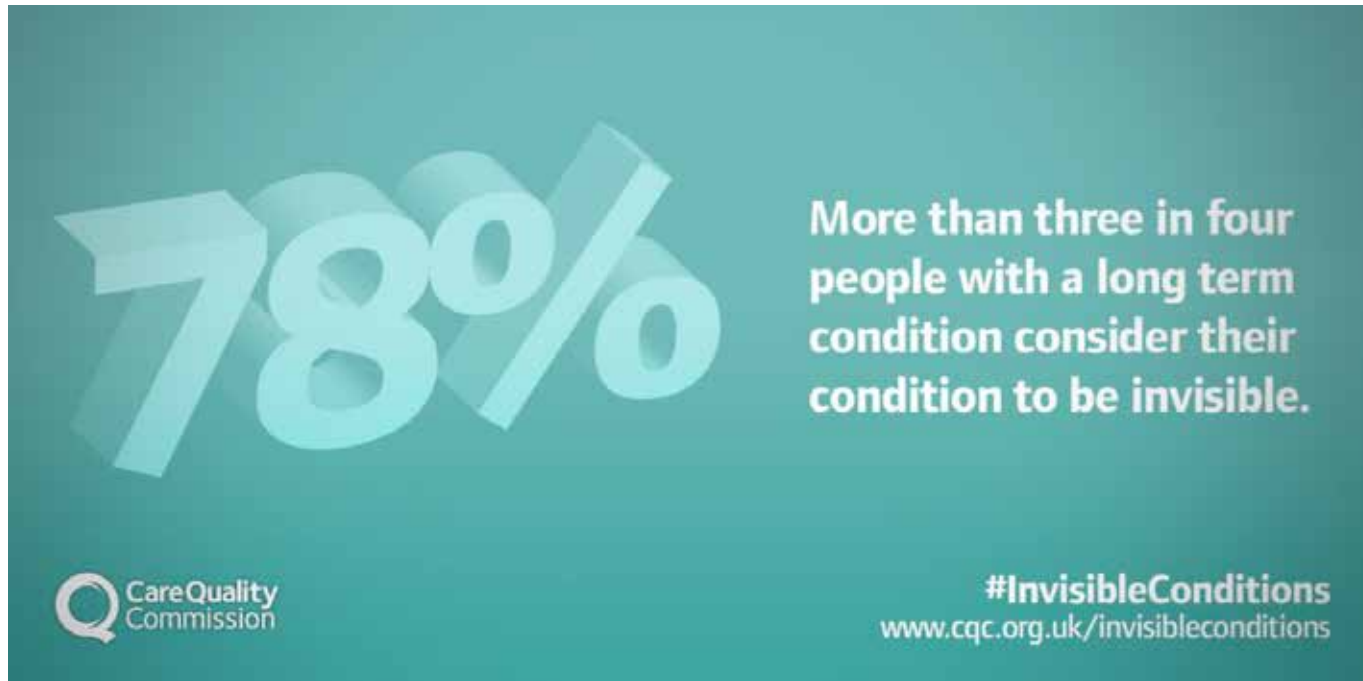
## Contents

Some key statistics

Nearly 70% **of expenditure on primary and secondary care is spent on long term conditions**

Self help groups provide a highly cost effective solution in the drive to increase and improve self care whilst reducing costs and improving outcomes.

www.selfhelp.org.uk/evidence/

15 million people

in England live with a long term condition (LTC)
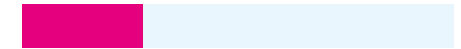
66% of people

who are aged 65+ live with two or more conditions

70% of NHS spend

is on treating people with LTCs

44% of our population

do not share decisions about their treatment, care or support

Foreword

An Introduction from the Co-design Group

As leaders of local support groups we have welcomed the opportunity to work collaboratively with Hastings Voluntary Action and Rother Voluntary Action on every stage of this important work examining the work of local peer led groups and how best it can be enhanced.

The conferences and networking events have brought together a large number and diverse range of groups. These gatherings have been a vital source of insight and intelligence but have also reminded us what incredible work is being done at a local level. We believe this work includes the largest ever survey of local support groups and we welcome the fact that our CCG and County Council have invested time and effort to review with us how best we can maintain an effective network of local support groups.

Receiving a diagnosis of a long term condition can be a really difficult time and as well as accessing good clinical services the ability to link with others who have been through this experience is vital.

Support groups are amazing places to share and think together, tackle common problems and support each other through the good and difficult times. Often overlooked is the fact that they enable people to feel they can make a continuing contribution to help others.

Moving forward there is much to be done and we hope that the recommendations in this report will be given serious consideration by those who shape local policies and services. We want to strengthen links with local NHS providers, create good pathways into local support and ensure that those involved in running local groups can access support and advice when they need it. We welcome the development of the new Self-Helpers on-line resource which has been launched at the request of local groups.

Finally, and above all we would like to thank the staff of HVA and RVA who led this work but most of all the local groups who gave generously of their time and insight to make this report possible.

The Co-design element

In developing a greater understanding of the role self-help groups play, it was imperative that this project was user-led.

Groups were invited to be part of an action planning group to take a lead in planning a much needed opportunity for reflection and dialogue between local support groups and health and social care professionals.

Although the groups are generally relatively small, together they are making a real and tangible difference to many local people – providing vital support as well as enabling opportunities for people to engage positively with each other, and create links with key health and social care professionals.

Increasing Levels of Activation

Level 1
Starting to take a role

Individuals do not feel confident enough to play an active role in their own health.

They are predisposed to be passive recipients of care.

Level 2
Building knowledge and confidence

Individuals lack confidence and an understanding of their health or recommended health regimen

Level 3
Taking action

Individuals have the key facts and are beginning to take action but may lack confidence and the skill to support behaviours.

Level 4
Maintaining behaviours

Individuals have adopted new behaviours but may not be able to maintain them in the face of stress or health crises.

A growing body of evidence underscores the importance of effective self-management of long-term conditions (Epping-Jordan et al 2004). People who are more 'activated' (that is, who recognise that they have an important role in self-managing their condition and have the skills and confidence to do so) experience better health outcomes (Greene and Hibbard 2012).

With effective support and education, evidence shows that these skills can be developed and strengthened, even among those who are initially less confident, less motivated or have low levels of health literacy (Hibbard and Greene 2013)

www.tinyurl.com/huwp9ca

Executive Summary

Recognising the value voluntary organisations can bring to helping people manage their own health, the Hastings and Rother Clinical Commission Group commissioned Hastings Voluntary Action and Rother Voluntary Action to undertake a pilot project that sought to develop a much better understanding of the local Self-Help 'community'. By this we mean the groups and networks that support people living with a long term health condition.

It has been recognised that these groups and volunteers play an invaluable role in helping people adapt and live with conditions that can be life limiting and by doing so, can positively contribute to a person's overall sense of health and well being.

The project sought to map the extent and reach of the local self help community with a focus on the top 10 local priority health conditions and then to engage in a dialogue about how groups can be best supported going forward.

Key amongst the recommendations is that relevant NHS processes engage with the self help community and we advocate that the local NHS consider how to enhance this mutually supportive relationship.

In the 2011 Census **23% of people in Hastings and Rother** were recorded as living with a disability or life limiting health condition, compared to **15% for the South East**

"A better understanding of multiple and complex needs."

Comment from Success flags from 2 March event

Project Timeline Key Milestones

Mar 2016   Project Commenced
Apr 2016   Identification of Groups
May 2016   Phase 1 Report
Jun 2016   Self Help Conference
July 2016   Action Planning Group Formed
Aug 2016   Phase 2 Support Agreed
Sep 2016   Self Help Website Launch
Oct 2016   1st Skills Building Workshop
Nov 2016   1-to-1 Support Commenced
Mar 2017   Network Events

Key Activities

- Identification and mapping of groups
- Visiting community access points, pharmacies, GP surgeries, PPG's to gain intelligence
- Design and hosting of a conference using 'asset based' approaches
- Agreeing future support actions and activities
- Delivery of skills building activities and training
- Development of the Self Help voice through the newly formed Action Planning Group

Key Findings

- Over 70 groups directly identified meeting CCG priority health conditions, a further 80+ impacting people with a long term health condition
- Majority of groups are very small
- Almost all totally run by volunteers
- Would like more support and help running groups
- Would welcome closer ties with formal health structures and clinicians
- Want to continue to have opportunities to meet as a network of groups
- Would like to develop their relationship with the NHS

The Role of HealthMakers
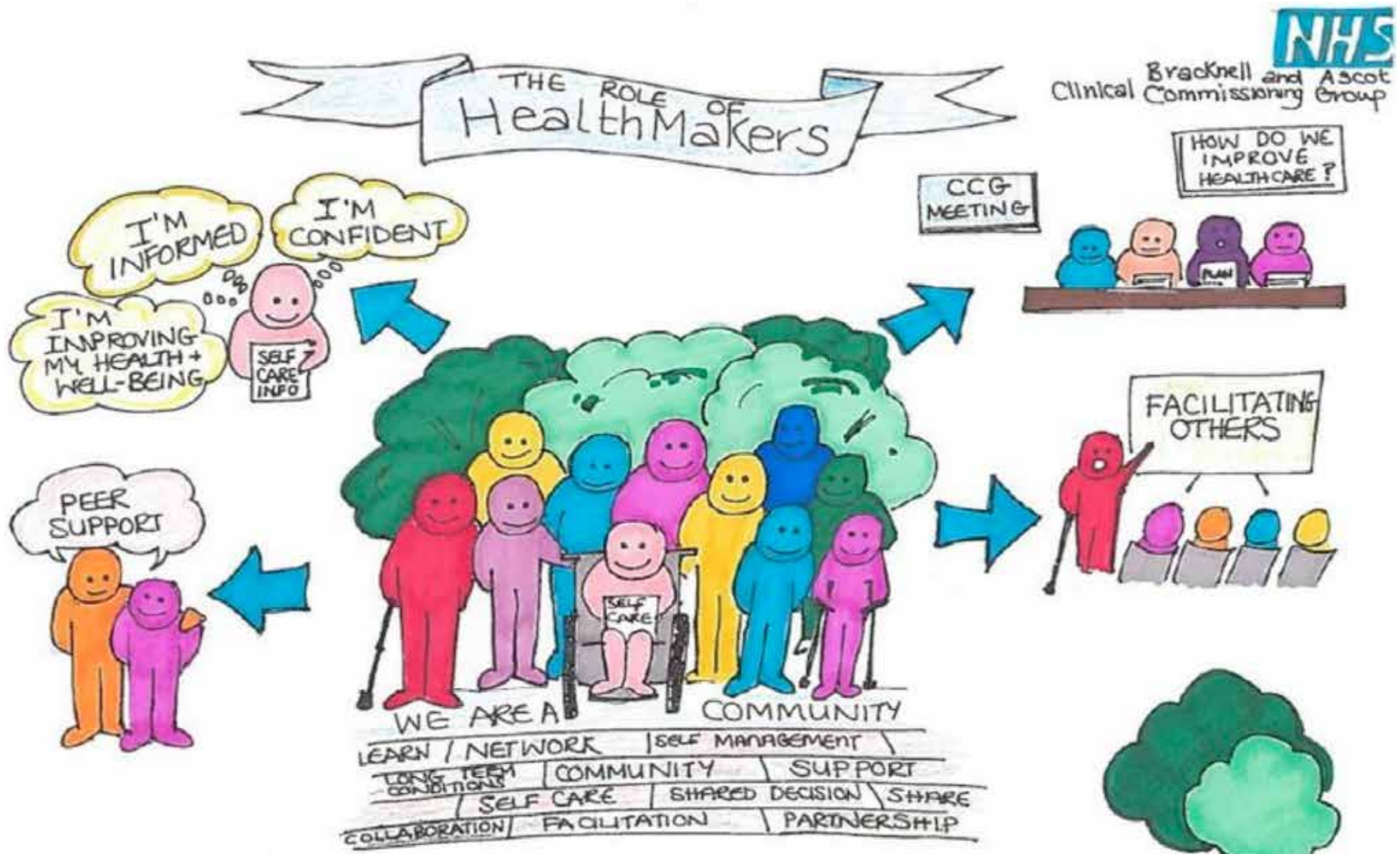
Solutions are best designed by local people for themselves. **Bracknell and Ascot Clinical Commissioning Group** has set up a community of **"Healthmakers"** to ensure people with long term health conditions are able to offer support to each other.

Background

Hastings and Rother CCG in conjunction with East Sussex County Council commissioned activity from Hastings Voluntary Action and Rother Voluntary Action to undertake a mapping exercise and set in place measures to support the development and capacity of local support groups for people with long term health conditions (LTHC) Specifically the aim of this project was to:

- Identify and engage existing self-help groups for people with long term conditions;

- Identify community assets that could contribute to the development of new and existing self-help groups;

- Work with self-help groups to support them in developing their groups

- Gain an understanding of the support and development needs of new and existing self-help groups and their potential to contribute to self-management;

- Co-design a toolkit of resources for new and existing self-help groups to enable them to sustain and develop activities over time; and

- Facilitate the development of a self-help group network for peer learning and mutual support

These groups have the potential to achieve wide reaching benefits: better mental and physical health, cost savings and wider social value . Hastings and Rother have significantly higher percentages of people with bad or very bad health compared with the rest of England with high rates of long-term illness, disabilities, cancer, lung disease and heart problems. Increasingly people living with these conditions are being asked to take a more active role in their own health management.

"DREAM: Self Help Groups Working Together as well as Health & Social Care Workers collaborating with self help groups.."
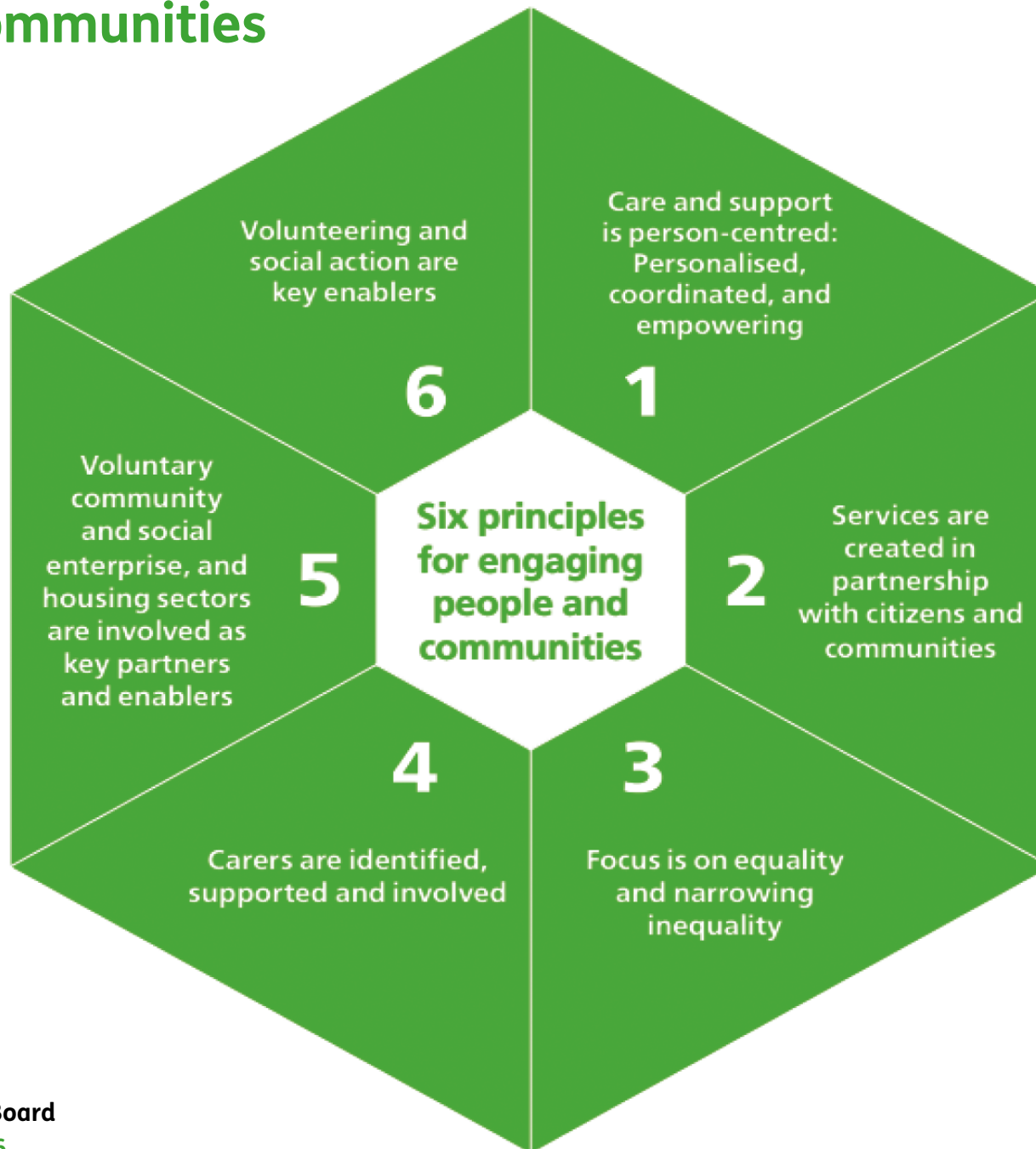
Comment from Success flags from 2 March event

"There is a body of evidence that peer support can help people manage the complexities of an initial diagnosis which can be bewildering and emotionally traumatic. Peer support can help people feel more knowledgeable, and reduce isolation."

Peer Support: What is it and Does it Work? NESTA and National Voices 2015

"Approaches that give people the support they need to manage their own health include (but are not limited to) self-management education; peer support; health coaching; and group-based activities that promote health and wellbeing. These approaches help people to build their knowledge, skills and confidence to manage their own health and care."

New Care Models: empowering patients and communities www.tinyurl.com/k7rxkrq

Engaging Communities

Care and support is person-centred: Personalised, coordinated, and empowering

1

Volunteering and social action are key enablers

6

Six principles for engaging people and communities

Services are created in partnership with citizens and communities

2

Voluntary community and social enterprise, and housing sectors are involved as key partners and enablers

5

Carers are identified, supported and involved

4

Focus is on equality and narrowing inequality

3

People and Communities Board

http://tinyurl.com/lpw3ua6

Project Delivery

From the outset it was decided that the project team would follow an asset based approach. By putting the community at the heart of the project the project team has ensured the project has established an approach that ensures that people often with a long term health condition themselves are able to drive the process in the direction and speed that they want it.

The project was formed of two phases:

Phase 1: Asset Mapping – sought to identify as many self help groups as possible and sought to go beyond formal directories by engaging with communities at a neighbourhood level to identify "hidden" assets as well as confirming the existence of known groups.

Phase 2: Co design – sought to work with the LTHC community to shape a support and development process that would enable them to identify and receive future support where and how they wanted. An Action Planning Group made up of people from LTHC groups was formed to help steer the project.

"Our strength is peer support but we need more people to know we are here."

Comment from Success flags from 2 March event

Asset-Based Values

1 Give support to identify and make visible the health enhancing assets in a community
2 See citizens and communities as the co-producers of health and well-being rather than the recipients of services
3 Promote community networks, relationships and friendships
4 Value what is already working well
5 Identify what has potential to improve health and well-being
6 Empower communities to control their futures and create tangible resources

Asset Based Principles (putting the values into practice)

1 Recognise assets: any resource, skill or knowledge which enhances the ability of individuals, families and neighbourhoods to create and sustain health and well-being.
2 Instead of starting with the problems, start with what is working, and what people care about.
3 Networks, friendships, self-esteem and feelings of personal and collective effectiveness are good for our well-being.

Community Values and Principles (from the engagement)

1 Context: Every place and community is unique, context is vitally important and activities or services must take account of this in planning and delivery.
2 Timescales: Recognise that community development takes time and may not be able to demonstrate effectiveness within annual evaluation deadlines.
3 Address the challenge of short-termism surrounding many funding regimes and project support faced by smaller community-based services and activity.

Asset Mapping

As part of the project a "live" map has been produced showing the location of voluntary groups supporting those with a long term health conditions. It can be found at: **www.tinyurl.com/k8v6nep**

Identifying the Groups

HVA and RVA Databases identified around 150 local organisations that might in one way or another be thought of as providing support for people with health conditions, with over 70 groups dealing with Hastings and Rother (H&R) CCG priority conditions (CVD, COPD, asthma, hypertension, diabetes, heart failure and stroke), mental health issues, autism and cancer support groups.

We also became aware of individuals with long term conditions who do not have access to any form of support groups. 22.8% of all residents of H&R report having a limiting long-term health problem or disability – a higher percentage than for both East Sussex (20.3%) and England & Wales (17.9%).

A short survey was created to assess some basic characteristics of the self-help groups. From our own expert knowledge RVA and HVA identified that the majority of the local support groups are small – typically being run with between 6 and 12 volunteers, tend to be entirely volunteer managed/user led and often receive little external support . Volunteers had, more often than not at least one long term health condition themselves or had a family member or friend affected by the condition the group was supporting. As a result they commonly reported the issues they faced whilst running a group and maintaining their own health and well being and the frustrations they felt when unable to meet the demands of the group on occasions where they felt too unwell to cope.

"My condition has become worse over the past two years and it is now affecting my cognitive abilities. It's now becoming really tough to remember things and I am always quite exhausted after the meetings. It is far more noticeable now."

Support group leader

Which (structure) best describes your group?
The most common structure was a registered charity (33%). The majority were formally constituted in some way (82%).

How does you group promote itself?
The most common reported method was word-of-mouth (89%) followed by traditional leaflets and flyers (74%). Social Media was only used by 54% of the groups.

Where do you hold your meetings?
Less than 20% specified that they held meetings across the entire Hastings and Rother Area. The majority (70%) described themselves as place based (e.g. Hastings / Bexhill / a village).

What types of activities does your group do?
Provides other health and well-being information (69%) and Encourages members to support each other (69%). Provides Activities (57%) and Provides advice/information about how to live with a specific health condition (51%). Provides information about the clinical details of a specific health condition (31%).

Roughly, on average, how many users/clients/members use the group on a yearly basis?
71% of the survey reported over 50 people using the group on an annual basis.

How many volunteers regularly help out running the group?
(44%) of groups reported that they had less than five volunteers. (47%) said between six and 20 volunteers.

If offered (types of support) would any of the following be of interest to you group?
Easy access to small grants (80%), Help finding volunteers (69%) Better links with NHS or CCG clinical staff (66%). Better links with other support groups e.g. forums, networks (51%).

How old is your group?
Most reported to being more than 10 years old. However, 10% could be considered to be relatively new (less than two years).

Active Participation

The conference made use of **Sli.do**, a smart phone based app that allowed us real-time feedback on presentations, allowed participants to vote in mini-polls and pose questions to presenters. It also allowed us to develop 5-minute debates around issues that resonated with participants.

The Conference

As part of the process a first area-wide conference was organised for both user led self-help groups that took part in the initial mapping and analysis phase of the project and others who wanted to attend. The conference was designed to enable the co-creation of future support network meetings for self-help groups. 60 people representing 34 voluntary organisations took part together with representatives from the Hastings and Rother CCG, East Sussex County Council, RVA and HVA

In organising the conference we were also aware that this work takes place in the context of a much larger programme of activity organised within East Sussex known as the Building Stronger Communities programme.
www.tinyurl.com/l6onrdd

This has examined ways of assessing and enhancing personal and community resilience to improve health outcomes. To maximise the alignment between our work and this wider programme we used much of the same appreciative inquiry methodology and configured around the same key questions:

- What difference are you making and what are you most proud of?
- What could help you do more of the work or do it better?
- What are your dreams and ambitions for the community you work with?
- What things could get in the way of achieving them?
- What key messages would you like to communicate to those working with communities?

"Social networking is providing a new landscape for patients to assemble health information, relatively free from the constraints of traditional health care."
**Social networks are The future for health care delivery,** *Social Science & Medicine*, **Frances Griffiths, Jonathan Cave, Felicity Boardman, Justin Ren**

The Appreciative Inquiry Approach

The format of the conference used an Appreciative Inquiry (AI) approach. This is a process for valuing and drawing out the strengths and successes in the history of a group, a community or an organisation. It is used to develop a realistic and realisable vision for the future and a commitment to take sustainable action. AI is not uncritical or naïve; it creates a positive mind-set by talking about success rather than being defined by past failures. The inquiry starts with appreciating the best of what is; thinking about what might be and should be; and ends with a shared commitment to a vision and how to achieve it.
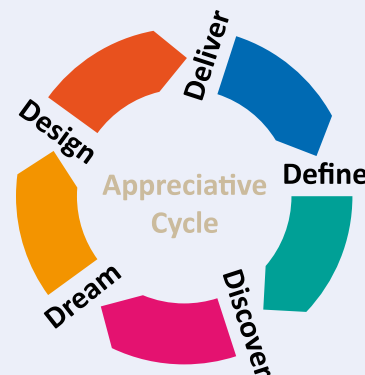
- **Define:** the people involved agree the positive focus of the inquiry.
- **Discover:** through storytelling and using interviewing and conversations, the approach draws out positive experiences and together people uncover common experiences about what works and what can be built on.
- **Dream:** people describe their dreams. This is presented as positive statements of what they would like their communities to be in an ideal future.
- **Design:** from collective experience people discuss what the ideal future in the community would be like
- **Deliver:** plan the actions to deliver the dream. How do we work together to deliver the ideal future? Who needs to be involved and what practical actions are needed?

People Centred
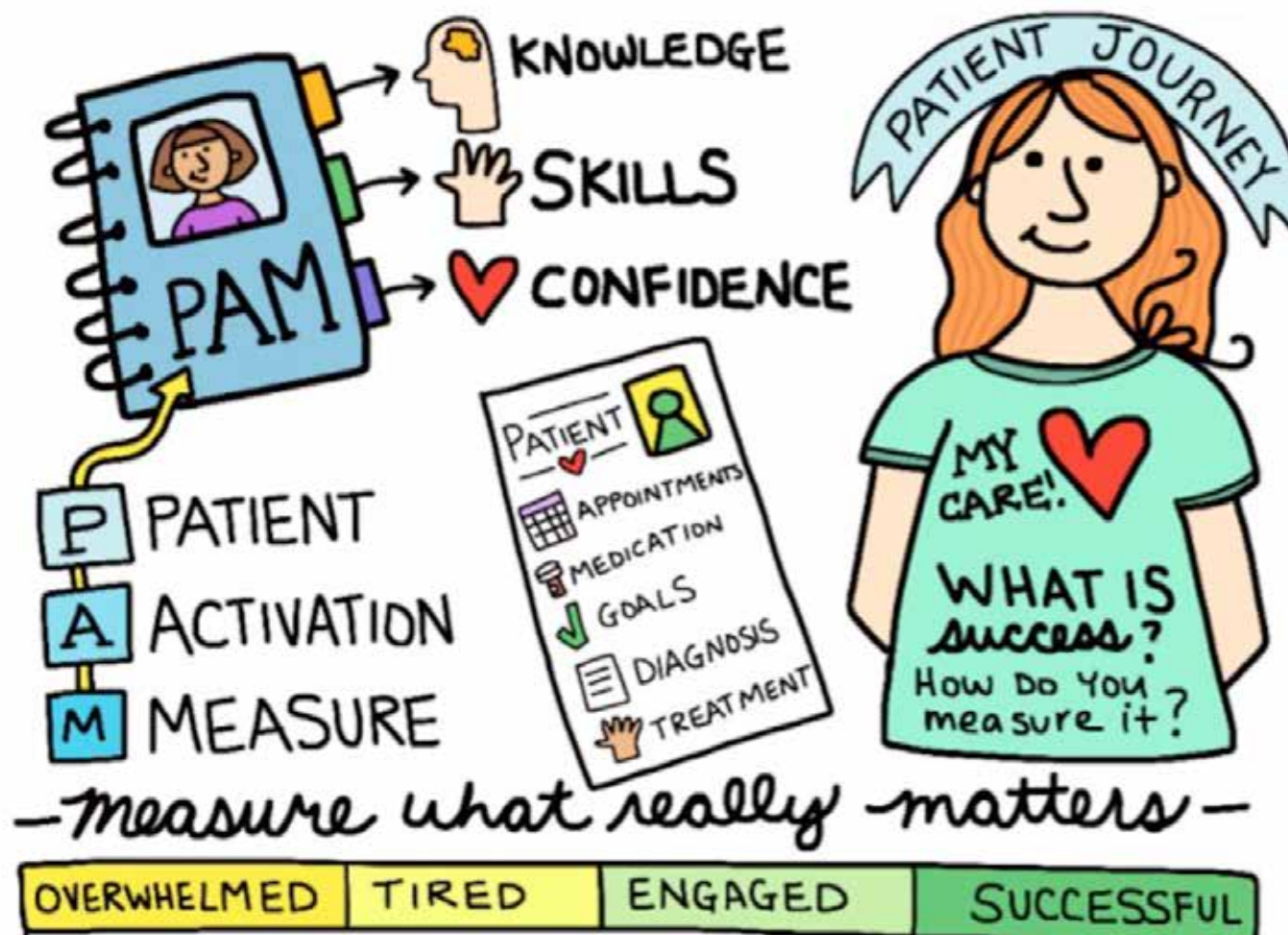
The QIPP guidance, 'Self-care support for long-term conditions' states: "there are potential net annual cost savings of £250 million from 2.3 million more people with a long term condition using information, a support group or skills training to better manage their condition". Research suggests that peer led support groups for people with chronic conditions have a cost benefit ratio of 34:1.

DoH. Accessed May 2010. QIPP Quality and Productivity. Self-care support for long-term conditions.
www.evidence.nhs.uk/qualityandproductivity

Learning from the Conference

The conference enabled participants to identify the resources, skills and knowledge already residing within the network and provided an opportunity for groups to voice their ideas and energy about the future.

Themes raised included the ability to network and collaborate with other similar or relevant organisations; having a "Voice" that is listened to and respected particularly within NHS structures; having groups led by people with a long term condition to provide the necessary empathy and understanding through lived experience; being able to share experiences and pass on knowledge; having some access to resources (funding, spaces, support) when needed on an ongoing basis.

A common theme was the fact that groups do not see themselves limited to focusing on all matters around a particular health condition, rather they provide an empathetic space where a range of discussions and activities can take place that are not directly concerned with health. Lastly, the difficulties of leading groups by people themselves having a LTHC was raised, and the effect on both the group leader and the groups own responsiveness and continuity.

Issues Raised by the Conference

- Finding volunteers is becoming more difficult
- Funding that is sporadic or hard to access
- Affordable meeting space
- Increasing demand on group leaders who themselves have a health condition
- Providing continuity of services as a group when health needs may take priority
- Coping with too many new users
- Knowing who to talk to within the NHS and how to engage
- Getting better known as a group
- Finding support around health conditions from the NHS

AI: Dream

As part of the Appreciative Inquiry process participants were asked to visualise a positive future for their group and express their hopes and 'dreams'.

These conversations were based on the things that people would like to see happening that would help them in the future.

Those participating identified the following as areas for further development:

Strengthening Communities (Communicating)

- Stronger, robust interface with the NHS / Connecting with clinicians
- More involvement at a strategic level around decision making and patient involvement Exploring what might be entailed in user led transformation

Collaboration and Partnerships

- Using Social Media and developing the Digital Health Agenda including lifestyle apps and tele-medicine

Volunteer and Peer Learning

- Networking and Peer Learning opportunities
- Skills development for self-management
- Promotion and social media training
- Exploring volunteering support and new volunteering models

Access to Community Resources

- Developing local responses to gaps in provision for support to include "pop up" lifestyle cafes in community settings
- Assistance with securing funding
- Support from external organisations (including local CVS) for running groups

Co-Design in Action

"We identified a shared goal for government, the NHS and the VCSE sector: to help people, families and communities achieve and maintain their own wellbeing. There was wide agreement that this is best achieved when people and communities are actively involved in co-designing systems and services.

The VCSE sector, therefore, has two vital roles:

1) To make sure people from all groups and communities get involved in the co-design process and

2) To help deliver more person-centred and community-based services."

Alex Fox, Chair VCSE Review https://vcsereview.org.uk/

"Discovering different areas of work is very useful. How can we help each other? What are our common goals? Good chance to find out."

"A better understanding of multiple and complex needs.

Networking.

Finding out about what other organisations are doing"

Comments from Success flags from 2 March event

Learning from the Self-help Community

Action Planning Group
All of the events, workshops themes and ideas came from the members of the self-help groups themselves who formed an action group to plan the work as below.

Networking Events
Apart from the initial conference there have been two networking events – each having a market place for organisations to learn about each and wider support services available, both with plenty of time to talk and to make connections.

Funding Workshop
Thinking about different ways of finding funding, such as approaching businesses or charities linked with a person's previous profession as well as advice on completing application forms and traditional funding opportunities.

Linking Professionals
An opportunity to ask questions directly to health and social care professionals and start connections with the people that can make a difference to lives of group members.

1:1 Support
All groups contacted and offered individual support around the groups itself, Some new groups have grown from this, such as Bulgarians in Hastings & St Leonards. Support was also available through the online resource – Helping Self Helpers

Using Technology and Social Media
Online resource and help to be part of this has been available. One to one support also offered around Facebook, Twitter and other forms of social media. Videos of the skills building workshops will also be available on the Helping Self Helpers site.

Skills Building Workshops
Workshops around what a group can offer to volunteers, how to interact with the press and effective press releases and the importance of having a website and connecting social media to this.


"A better understanding between clients and the NHS and the wider community."

"To develop a strong working link between the voluntary sector and NHS teams and other AHP."

"We would like the NHS and CCG to know we exist. Help us to work with all those in East Sussex who are involved with Dementia.

To the CCG we say: thank you for your support. We are doing the best we can."

Comments from Success flags from 2 March event

An individual's perspective: Web of Care
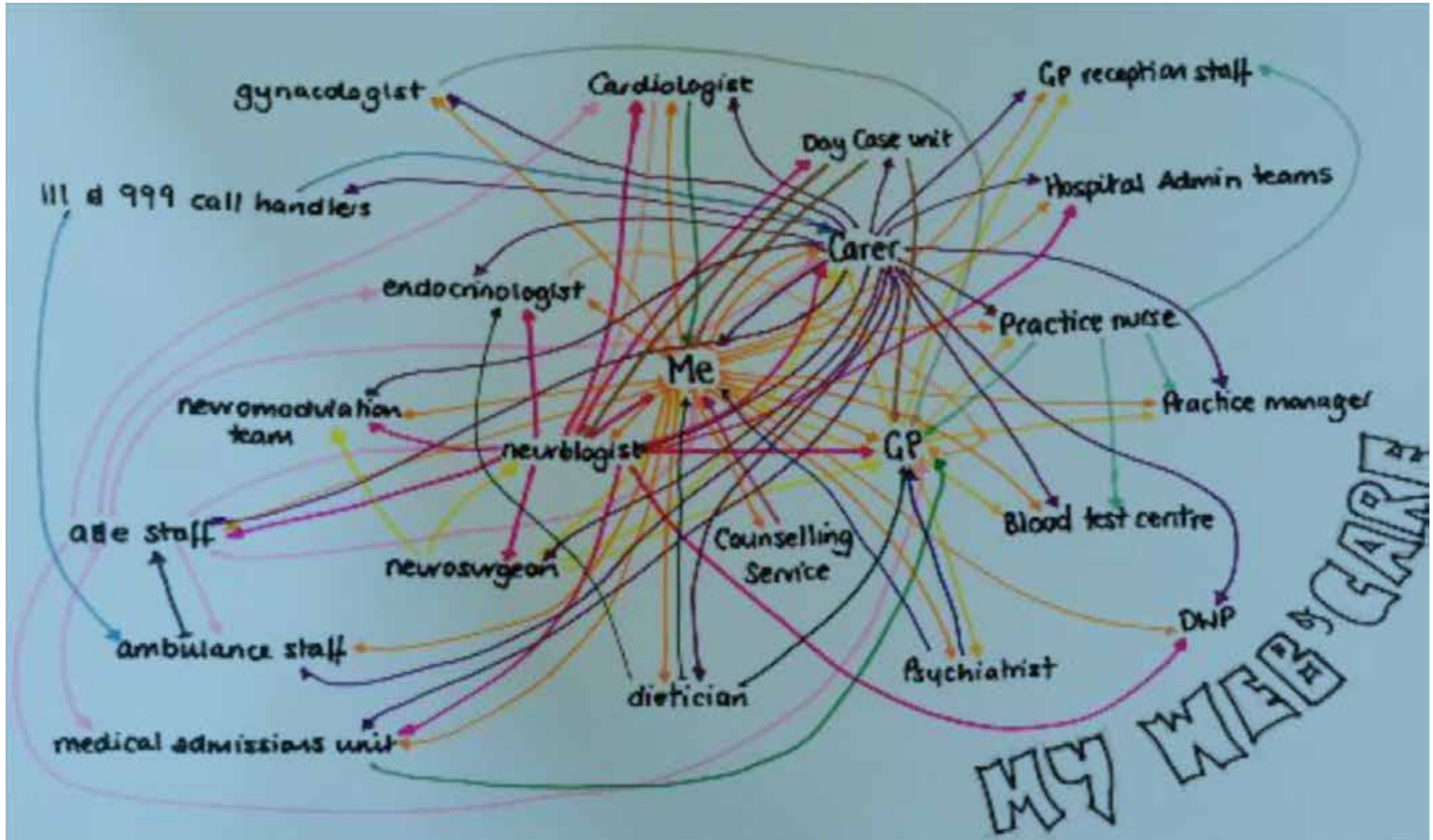
From East Sussex Self Care Summit 2016 : Katie Clarke-Day

Working with Diverse Communities

The user led nature of the project has enabled voices from all communities, and especially marginalised, minority and diverse groups to be heard, incorporating group resilience, successes and/or barriers to support linked to long term health conditions.

We were keen to ensure that the Helping Self Help Project reaches all communities, to explore any barriers to seeking help and whether services are adequately and appropriately meeting the needs of our increasingly diverse communities.

Using our contacts within the project, a range of ethnic minority and/or diverse voluntary sector groups and service users were consulted which included:

- Links – a multi-agency partnership that provides support and advice to asylum seekers, refugees and migrant communities living in East Sussex;
- Hastings and Rother Rainbow Alliance Transgender Group;
- Hastings Older People's Ethnic Group;
- Hastings & Rother Disability Forum;
- The Chinese Association;
- Bulgarians in Hastings & St Leonards,
- as well as young people's voices from the Hastings Youth Council.

In keeping with the asset based approach, honest communication, a willingness to engage and co-design, diverse and ethnic minority groups have fed very positively into the research for the project throughout. This included involvement at networking events, workshops and 1:1 group engagement.

Further information on some of the key messages from marginalised and diverse communities can be found in **Appendix 3**.

*"The Group was a Single Cultural Group but has been so successful it has become an International Group!
We may have to change our Name.
I'm Proud of this."*

Comment from Success flags from 2 March event

Key messages from marginalised and diverse communities:

- Safe places
- Better social media presence for services
- Affordable meeting space
- Lack of funding
- Non-religious places
- Open communication of systems, processes and entitlements
- Knowing who to talk to within the NHS and how to engage
- Good relationships with GPs
- Fear of authority
- Finding non-discriminatory support from the NHS around health conditions
- Holistic approach to services
- Peer support is essential

Providing online help

http://selfhelpers.rva.uk.com
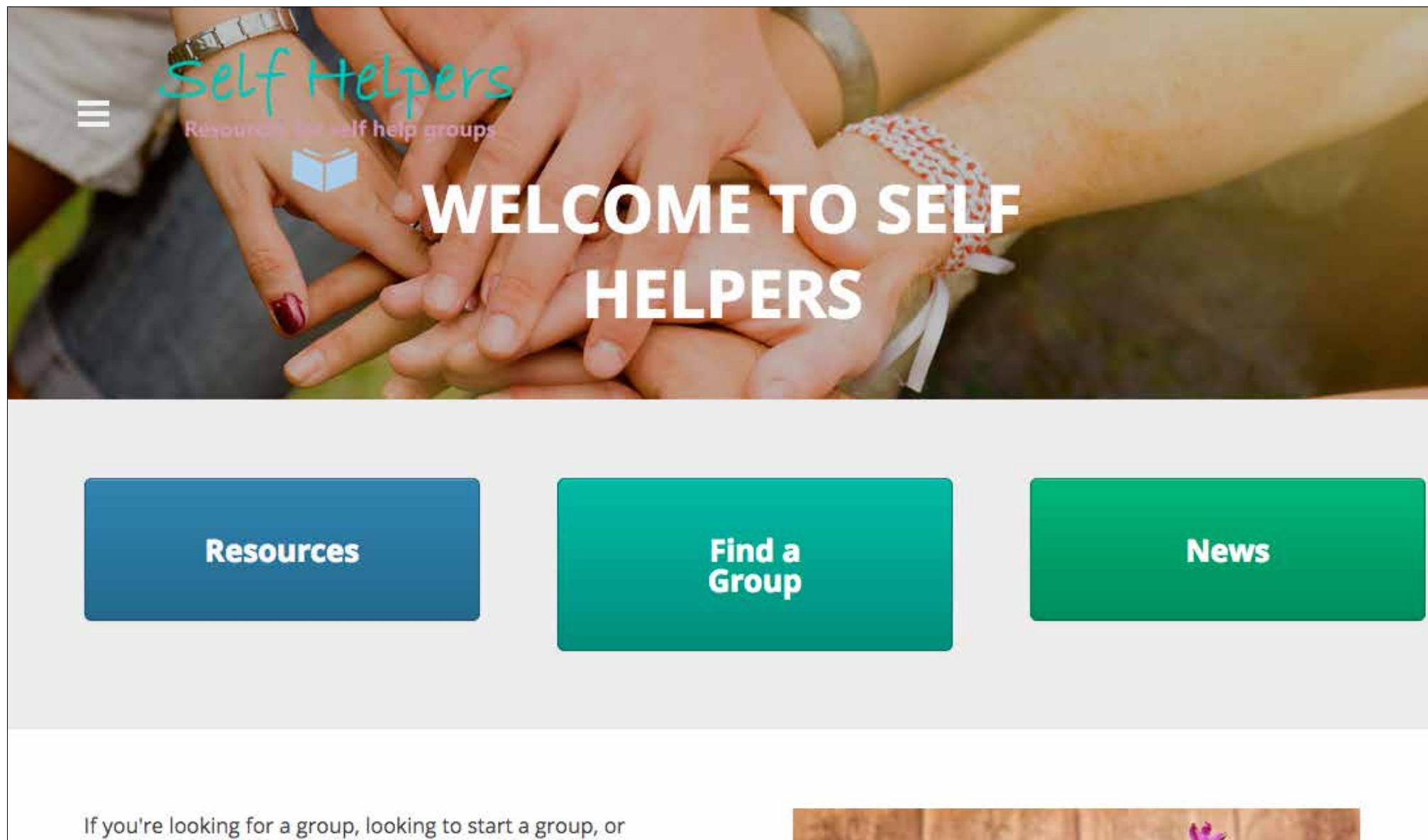
The Self Help E-Resource

Based on what the Self-Help community told us in the conference we identified that a clearly identifiable local web based presence would enable the Self Help Community to develop more visibility online and act as a resource repository, enabling groups to post ideas and news.

http://selfhelpers.rva.uk.com was created as an affordable and easy to use site. The site is still in development and latest changes have been to improve the readability for partially sighted people and ensure that e-readers can make sense of the content. Part of the process is to encourage groups to make more use of social media and social networks and develop a degree of digital confidence. Training and support has been offered in helping develop Facebook groups. However take up has been slower than expected. Some of the reasons for this seem to be levels of energy and confidence to learn new skills, fear of promoting the group too widely and gaining larger numbers or raised expectations as the result of a higher profile.

Despite these challenges, engaging with social media for some groups brings with it a number of practical benefits. The running costs of a group can be reduced and it can provide quick way of sending out and receiving information including updating members on a range of issues and developments. In addition to the practical group benefits, social media can provide some group members with an additional layer of connection and peer support, as some members are using Facebook to remain in contact with each other outside group meetings as friendship circles not soley concerned or talking about their health condition.

"Self Helpers website"

"Groups feeling confident to use online material & keep their own information up to date on websites and directories."

Comments from Success flags from 2 March event

During the initial mapping it was noticed that many groups still prefer word-of-mouth advertising or print posters. One of the themes emerging from the conference was confirmation of a reluctance to engage with digital technology by many groups especially to promote themselves and connect with possible users.

Equally it was a widely shared experience that finding useful, relevant and preferably local online (or print) information and sources of support around self help groups was extremely difficult. Groups appeared often in different private, public and business online and print directories and in many cases nowhere at all.

Groups themselves reported they did not know where to go to find useful sources of information especially when first starting up.

As a result, the Self-Helpers website was developed in order to provide an immediate solution to digital visibility for groups; provide a place where self help groups can go and post content including their meeting details; and provide a "digital identity" to encourage the further development of the Hastings and Rother Self-Help Network. It was also intended that by showing what could be achieved quickly and inexpensively it may be possible totbreak down some barriers around using social media. RVA and HVA have been supporting individuals to extend their use of social media by working with them to develop no cost social media groups.

What's Important to Groups?

The most common words recorded from feedback at the June 2016 conference

Impact

Asset Mapping – Finding support groups

We found groups ranging from the high profile to the tucked away neighbourhood groups and none at all. If you have atrial fibrillation there are no local groups, however support available online through AF Alliance or groups such as Downs Heart.

Creating Peer Networks and an Interface for Discussions

Groups said that they wanted to talk to each other and professionals and establish connections. As a result of our networking : "thanks to this lunch opportunity I have been able to get in touch with someone to help with my facebook page"

Creating Potential Connections with Clinical Staff

An initial workshop was held with representatives from groups and clinical staff. Questions ranged from supporting members of your group requiring medical help, asking speakers to attend meetings and information about support being known to relevant professionals.

Building Capacity and Capability

The community wanted workshops to help build their skills and knowhow. We used mini workshop sessions around topics the community identified. East Sussex Dementia Support were really pleased to receive help with their social media.

Developing Confidence

At the outset of the project groups felt isolated and were unsure how to make connections with each other or statutory authorities. After three network sessions participants feel more able to engage with each other and formal NHS structures.

"We weren't sure whether we would be taken seriously but we see now there is genuine interest in what we do."

Creating Health Benefits Through Support to Individuals

Having a stronger LTHC structure means more individuals will be able to receive the support required to sustain their health and wellbeing. People have identified that being part of a group helps them remain a whole person and not just a set of symptoms and that their view and voice can be heard and taken seriously by those commissioning services.

Better Understanding of the Challenges Facing Self Help Groups

The biggest challenge facing most of these groups is the fluctuating capacity of those with medical conditions running the groups themselves. Hasting and Rother Disability Forum is currently unable to do much due to the illnesses affecting all of the current committee.

Laying the Foundations for Greater Investment in Support Groups

Groups have said that they greatly value the support they have had. There is a desire to continue networking and learning but no capacity to do this themselves.

"These events are important but we need your help to do them"
Eastbourne Fibromyalgia and ME Support Group

Identifying What Can Be

Opportunities identified by participants at the June 2016 conference

Recommendations

Celebrate:
The range and diversity of local support groups is a real asset to the local health and social care economy and to those living with long term conditions. We recommend that health and social care partners celebrate the work of local groups with an annual celebration event or conference. This would help strengthen links with health and social care professionals and explore further steps to enhance the peer support sector.

Upskill:
The nature of peer led support is changing and the role of social media creates both a massive opportunity but also some challenges for groups to enable support, and respond to the emergence of this new trend. It is recommended that a further training and support offer around the use of social media by peer support groups be co-designed and offered. We have identified other training needs and responded to them.

Expand:
We are finding that support groups are tackling issues which are condition specific, but also topics which are much broader. The recent change from Disability Living Allowance (DLA) to Personal Independent Payment (PIP) is one example of this. We recommend that ways are explored to expand contacts with advice and advocacy services.

Strengthen:
Links with clinical leads can be vital ways of maintaining up to date information and developments around a range of conditions. But it is currently piecemeal and is largely built around the relationship with individual peer group leaders and local consultants. We recommend that the CCG explore ways in which this could be made more consistent and enable more frequent clinical updates.

Support:
We have found that local support groups are vital but can be fragile as the health of their leaders can change over time. We recommend that further work be undertaken to look at the provision of group support, but also share good practice so that issues of cover and succession can be considered.

Inform:
We would like to increase local awareness of the work of support groups, as well as explore ways in which the knowledge of peer led opportunities could be developed amongst relevant front line staff such as pharmacists, personalassistants, health visitors etc. We recommend that this be considered as part of the wider workforce development strategy.

Go Local:
We recognise the emphasis being placed on locality working and the creation of locality link workers to create meaningful pathways to local community services. We recommend that further work is undertaken in Hastings and Rother to ensure the role of peer led groups is recognised and ingrained in the locality teams. We were pleased to welcome both the Hastings and Bexhill locality link workers, who were involved throughout the process.

Support spaces:
The need for local venues and spaces in local communities has been identified through this work. We welcome the emphasis the CCG are placing on the creation of Community Health Hubs and the investment they are making to make these more sustainable. We recommend that opportunity to create strong links between these emerging hubs and local support groups be explored by the CCG as part of the next stage of the commissioning process.

A Participating Community

Co-designed – participating groups and groups identified through mapping conference

Appendix 1: Active Involvement

The project was designed around identifying, encouraging and enabling groups to have a stronger say in what they would like to see in place that would make their lives easier, their groups better and most importantly the health and wellbeing of group members helped.

To that end we have:

- Supported the development a peer support network (Self Helpers) for local groups to get together and share

- Underpinned the network with a web based resource maintained by RVA

- Encouraged groups to access resources such as small grants that are available and helped them do so

- Provided 1:1 support to overcome barriers that they identify

- Brokered relationships with local health professionals to strengthen connections with formal health and social care structures

I have only just seen your email with regards to the survey (which I have done) my apologies for the late-ness of filling it in, but when you run a support group and also are a sufferer sometimes emails do not get answered as quickly as I would like. I am very interested in your help, so I really hope you will be able to.

We would like to acknowledge the presence of CCG staff at the event. This was an encouraging factor and we are very keen to continue our association with this event...

My involvement in this project has also given my group service users a voice for things they otherwise may not have expressed.

I am the only Dementia champion going out to give talks right now, and after a period of ill health too, I need support

Don't give up, even if it seems like you are only helping a couple of people, it makes a big difference to them.

Appendix 2 : A Participant's View

Louise set up MoDS (Memory or Dementia Support) in 2015 and runs the group as a volunteer led self-help support group for anybody diagnosed with or affected by Dementia or memory loss, their friends, family and carers. Prior to this, Louise's career was working with and supporting people with Dementia, and their carers. Louise also lives with a number of chronic and long term health conditions herself, so is speaking as both a Volunteer Co-ordinator as well as a service user.

These are Louise's words:

"Human connection is important because the groups work on a person-to-person level and that's the approach that works for most of the facilitators. We need to recognise that not all are computer literate or, for whatever reason, able to access information electronically. You need a contact point to signpost. It's a lot about the structure of how groups work because the groups are all person-orientated. It seems silly for the group leaders not to have that as well – it's very much needed. This project has done that for group leaders – receiving support on a par to what they're providing. A lot of issues leaders come up against are very complex – knowing the people asking for support means that we know all the variables – just typing a question into a search engine is not useful! Being part of the Helping Self Help support group has meant that I've received information on available training for ESA / PIP access, which I've attended. This has resulted in being able to support group users who for various reasons such as poor literacy, lack of computer skills and lack of confidence, would other wise not have been able to access what they're entitled to. Picking up a leaflet would not have helped – the benefit system is in such a state of flux, which in itself is a barrier to most people. Access to face-to-face group support and facilitation throughout the project enables better access to peer support, training,

knowledge and information and support to be able to support our own group users in a much more informed way with confidence.

When I've gone back to MoDS and told them about what I've been up to or got planned, they've been really keen and welcomed that. My involvement has also given them a voice for things they otherwise may not have expressed. It was important to be involved in this on a couple different fronts: It's nice to be heard and feel you're genuinely heard and not just a box-ticking exercise. I found that the vision I had was very close to the vision the commissioners had – it feels like there's some co-operation in my future health care. It is about self-care – as in we will do this together. It was an excellent opportunity to show that there is joined up working and thinking between commissioners, service providers and service users. Our support groups prove that people working together and communicating together can achieve meaningful results, and it's nice to see that mirrored and taken seriously, in the planning of services that we all access. The direct feedback I've received from Health and Social Care Professionals who attended the conference, has been inspiring and positive. It is a huge boost to me personally and professionally to know that my career and personal experience is of use to the people making decisions about future self care and self management around health."

Appendix 3: Working with Diverse Communities

Enabling voices from all communities, and especially marginalised, minority and diverse groups to be heard, incorporating group resilience, successes and/or barriers to support linked to long term health conditions.

Hastings and Rother Rainbow Alliance Trans Group

In our peer support group, quite a few of us have long-term health conditions including family related ChD and Hypertension, Macular Degeneration, Stroke, significant mobility problems from an accident and some long term mental health issues. Most of us live very active lives and/or work and exercise regularly: All of us I would say benefit from having a peer support group and some of us may be quite isolated without it and without us may rarely go out. Younger people don't really come to our group meetings as there is a local LGBT youth group and also social media which seems to suit them better but we have a Facebook linked 'network' and encourage people to meet together in small groups and make friends which does seem to happen. Personally I think for some people, especially the older ones with LTHC – groups like ours are essential lifelines. It's the people with health conditions who tend to keep coming. Others transition and move on when they no longer need us. As leaders of the group, we meet people one-to-one if they don't feel able to come to the group. We also keep contact through email and Facebook. We have different people who help support people of similar ages and interests, some of whom have disabilities that impact upon their abilities to participate in group activities. One of our greatest challenges is a lack of finance for providing support for members, for example to go to clinic appointments in London. Money, time and training for peer support for appointments are the top three things that would make running our group easier.

G / Hastings & Rother Rainbow Alliance Trans Group

Hastings Youth Council

Young people said they would go to their GP for support; but that better social media presence would help them to know about any services out there that could help them.

Emile Tambeh / Community Cohesion & Support Officer

The Trans Community

The Trans Community is arguably the most fragile, vulnerable and fractured group within society. Access to healthcare, (physical and mental health) is not always easily accessible when healthcare is being obstructed due to Transphobic practitioners. Safe spaces and access to mental health with professionals who are able to help with the Trans community, are current challenges and key messages.

NS / trans individual

The Links Project: Supporting BME Groups with LTHC

The Links Project is a multi-agency partnership providing access to support and advice to asylum seekers, refugees and migrant communities living in East Sussex. The Links Project relies heavily on informal engagement. The primary objective of the project is to create a safe and welcoming space at the drop-in that belongs to the service users and has no barriers to access. From there we build on supporting individuals but also gathering evidence of experience that can be fed into strategic planning and service delivery development.

Through the Links Project staff team's interactions with the service users, we are able to identify common barriers to accessing support. These barriers can include a lack of understanding of systems, processes and entitlements; they are also caused by a fear of authority. We have found that in some cases the shared experience is the starting point for contact, which then develops into positive personal friendships between individuals. It is unlikely that this would be thought of as being a "community" as defined in the asset based approach and so the methods of engagement become difficult to apply. Having said that, in the context of supporting each other with long-term health conditions, a strong friendship is much more likely to result in positive physical, emotional and psychological support.

Marc Turczanski / Links Project Co-ordinator

Great to meet others!

Learnt a great deal!

Full of useful information – well organised!

Good networking, very helpful information

"A chance to meet fantastic organisations and network with them to improve wellbeing and health in our community"

"Positive networking environment that helps to make groups feel they are connected"

"To develop a strong working link between the voluntary sector and health & social care professionals"

" It has been good to have the opportunity to come together and share – ways need to be found to continue this."

Comments from Success flags from 2 March event

Inspiring & innovative

Turning negative into positive with Self Help

Better links with other services