

## Access to Community Resources

- Developing local responses to gaps in provision for support to include “pop up” lifestyle cafes in community settings (e.g. Hope Café)
- Assistance with securing funding
- Support from external organisations (including local CVS) for running groups

‘This event identified a gap in support for self-help groups and provided an excellent opportunity to network, promote services and initiatives and provide peer support.’

## Next Steps

The conference enabled those attending to work through the first three elements of the Appreciative Inquiry model (Define, Discover, and Dream). The conversations were very useful and helpful in determining how the final two stages of the Appreciative Inquiry model (Design and Deliver) could be approached. It was agreed that these would be best carried out as follows:

## 4 Design

From collective experience people discuss what the ideal future in the community would be like.  
- A User Led Action Planning Group (APG) to design the support and development ideas further has been formed during August 2016.

## Annex A – List of Participating Organisations

Amicus Housing	Hastings and Rother Disability Forum	Rother Seniors Forum
British Sign Language Link for Communication	Hastings and St Leonards Seniors Forum	Red Cross
Deaf Cultural Outreach Group	Hastings Dementia Action Alliance	Remark!
Dementia Support at The Bridge	Hastings Older People’s Ethnic Group	Rother Voluntary Action
East Sussex Local Pharmaceutical Committee	Hastings Voluntary Action	Seaview Project
East Sussex Recovery Alliance	Hastings Your Way	Southdown Housing
Fulfilling Lives South East	Imago Community	Special Kids
Hastings and Rother Clinical Commissioning Group	Memory or Dementia Support	The Sussex Association for Spina Bifida and Hydrocephalus
	Mind Hastings	Sussex Community Development Association
	National Autistic Society	The Y Centre
	Ore Community Centre	Together UK
		Tomorrow’s People

## 5 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?

– HVA and RVA assisting the User Led Action Planning Group (APG) to work with Hastings and Rother CCG to develop a plan of action to end September 2016 including the following:

- 1 APG meeting
- 1 Networking event
- 1 Workshop
- Web resources

– As well as support for a further action plan to be implemented October 2016 to March 2017, including:

- 3 APG meetings
- 1 Networking event
- 4 workshops

– We would also recommend a trial pop-up café – peripatetic support service in Hastings and Rother.  
– HVA and RVA assisting the User Led Action Planning Group (APG) to work with Hastings and Rother CCG to develop a further plan of action to be implemented hopefully in 2017/18

## Feedback

Those attending the conference were asked three questions:

- Did you find today useful? Yes = 20 No = 0
- Would you like further opportunities to meet with like-minded people? Yes = 18 No = 0
- Was the venue suitable for your needs? Yes = 18 No = 0

## Annex B – Results of the Conference mapped against East Sussex Better Together Community and Personal Resilience work streams

### Communication & collaboration

#### Successes

- Technical & moral support from external organisations including infrastructure organisation
- Ability to network and collaborate with other similar or relevant organisations
- Having a ‘voice’ that is listened to and respected particularly within the NHS structures
- Being able to share experiences, pass on knowledge
- Having access to resources (funding, spaces, support) when needed on an ongoing basis
- Being able to effectively promote and market the group

#### Opportunities

- Affordable meeting spaces
- Knowing who to talk to within the NHS
- Getting better known as a group

‘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...’

### Volunteering

#### Successes

- Having a group of motivated volunteers

#### Opportunities

- Finding volunteers
- Being able to provide continuity of services as a group when health needs may take priority

### Resources

#### Successes

- Having a ‘voice’ that is listened to and respected particularly within NHS organisations
- Having access to resources (funding, spaces, support) when needed on an ongoing basis

‘Loved the method used for feedback using tokens into jars and would use this for my own activities.’

#### Opportunities

- Finding volunteers
- Funding that is sporadic & hard to access
- Affordable meeting space
- Increasing demand on group leaders who themselves have a health condition
- Being able to provide continuity of services as a group when health needs may take priority
- Coping with too many new users
- Finding support around health conditions from the NHS

We would like to take this opportunity to thank all involved alongside Hastings Voluntary Action and Rother Voluntary Action in volunteering their valuable time to help achieve a successful conference

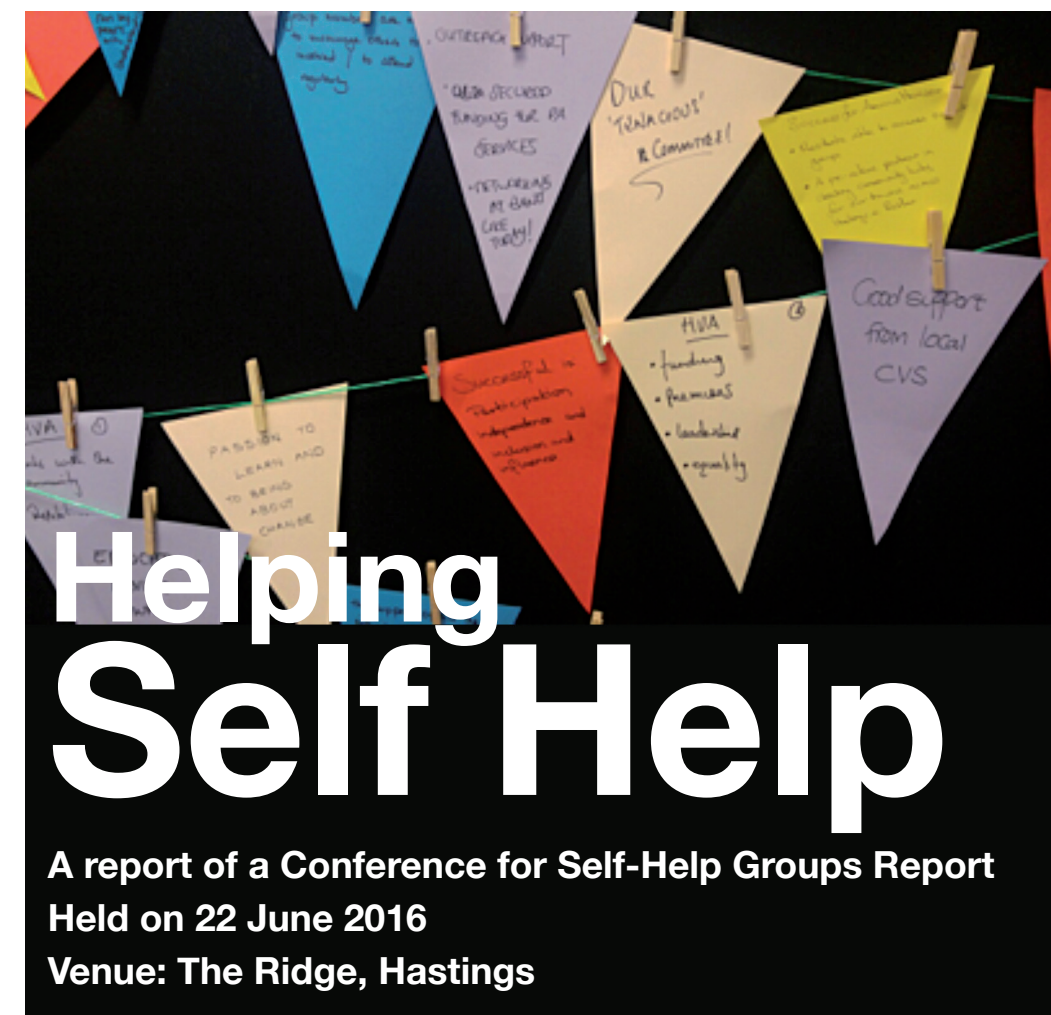
#### Co-designing and co-hosting:

Becky from East Sussex Resilience Alliance  
Rosemary from Hastings and Rother Disability Forum  
Louise from Memory or Dementia Support

#### Photography:

Dean at Deathprone

Table facilitators: for gathering all the comments and feedback so efficiently



## Introduction

When you are first diagnosed with a condition or are faced with long term health challenges the support of people who have been through the same experience is invaluable.

As the leaders of local support groups, we were very pleased that the Clinical Commissioning Group were interested in developing a greater understanding of the role we play. We also appreciated being invited by HVA and RVA to help organise and develop a local conference.

It was a unique event led and supported by the groups themselves and the energy and enthusiasm on the day led us to believe that it was a much needed opportunity for reflection and dialogue between ourselves and with those working in the NHS.

As far as we are aware this was the first occasion all the support groups had met together in this way and we very much hope it won’t be the last!

We are continuing to work with HVA and RVA, together with colleagues from the Clinical Commissioning Group to take forward the conclusions of the conference and ensure that the needs of local support groups are reflected in any future work.

We are very pleased to produce this brief forward to the report which we hope you find informative. Although we are relatively small support groups, together we know that we are making a real and tangible difference too many local people living with long term conditions, providing vital support as well as providing positive opportunities for people to engage positively with each other and create links with key health practitioners.

**Becky James**  
East Sussex Recovery Alliance

**Louise Smith**  
Memory or Dementia Support

**Rosemary Iddenden**  
Hastings & Rother Disability Association





## Method

RVA and HVA have been commissioned by Hastings and Rother Clinical Commissioning Group to identify the support self-help groups in Hastings and Rother may require, develop a delivery approach and agree a set of actions that will assist self-help groups to thrive.

As part of the process a conference was organised for user led self-help groups that took part in the initial mapping and analysis phase of the project. The conference was designed to enable the co-creation of future support for self-help groups (see Annex A for a list of attendees/groups).

In organising the conference we were 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. 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 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?

By adopting this approach we were able to increase our understanding of the resilience of local peer led support group and reach consensus about ways of maximise this network of group as a key asset for patients carers and families.

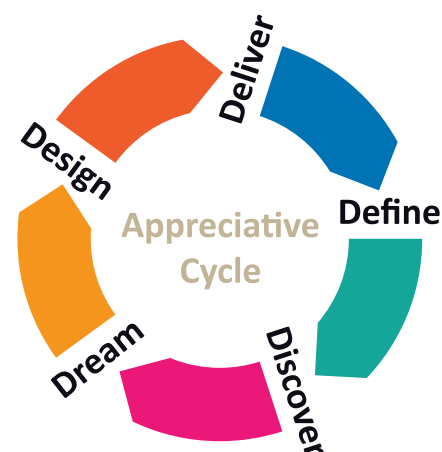
“Great use of technology to engage and get live feedback.”

To achieve this we also constructed the format of the conference around the following **Appreciative Inquiry** approach:

- 1 Define:** the people involved agree the positive focus of the inquiry.
- 2 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.
- 3 Dream:** people describe their dreams. This is presented as positive statements of what they would like their communities to be in an ideal future.
- 4 Design:** from collective experience people discuss what the ideal future in the community would be like.
- 5 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?

**Appreciative Inquiry (AI)** is a process for valuing and drawing out the strengths and successes in the history of a group, a community or an organisation. This is used to develop a realistic and realisable vision for the future and a commitment to take sustainable action. AI is not an uncritical or naive approach; 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.

The conference also made use of **Sli.do**, a smart phone based application that collects real-time feedback on presentations, by enabling participants to vote in mini-polls and pose questions to presenters. It also allowed us to develop 5-minute debates on the fly around issues that resonated with participants. **Sli.do** greatly assisted us in making the event more about co-creation than simply one-way feedback presentations often allow.



### 1 Define

**Agree the positive focus of the inquiry (supporting and developing self-help groups)**

- To understand the contribution of peer led support groups and develop ways of supporting current and future activity so that this key asset for those living with Long Term Health Conditions is maximised.
- Initial research indicated that:
- Hastings and Rother has a diverse network of peer led support groups linked to specific medical conditions although there were some ‘gaps’ where some targeted development could be undertaken to explore whether there was a wish to establish peer led support.
  - Links with NHS providers were variable and groups wished to strengthen and consolidate relationships with NHS practitioners to both make referrals easier and obtain help or information needed by the group.

### 2 Discover

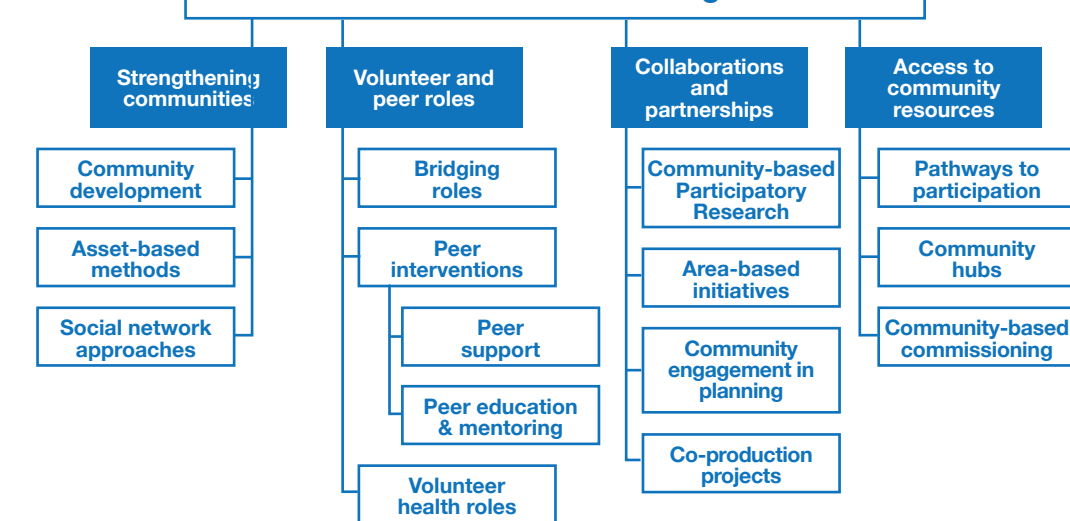
Capturing the positive experiences and the key success factors in running a self-help group

**Successes in running a self-help group**

- Technical and moral support from external organisations including infrastructure organisation
- 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, pass on knowledge
- Having a group of motivated volunteers
- Having access to resources (funding, spaces, support) when needed on an ongoing basis
- Being able to effectively promote and market the group

‘Well thought out content to gain and share valuable information while allowing ample networking opportunities.’

## Community-centred approaches for health & wellbeing



### Opportunities identified by Conference participants

- Finding volunteers
- Funding that is sporadic or hard to access
- Affordable meeting space
- Increasing demand on group leaders who themselves have a health condition
- Being able to provide 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
- Getting better known as a group
- Finding support around health conditions from the NHS

The findings were further organised using the approach laid out in Public Health England’s “A guide to community-centred approaches for health and wellbeing”.<sup>\*</sup> Community empowerment occurs when people work together to shape the decisions that influence their lives and health and begin to create a more equitable society. This is not about a DIY approach to health; there are important roles for NHS, local government and their partners in creating safe and supportive places, fostering resilience and enabling individuals and communities to take more control of their health and lives. Community-centred approaches are not just community-based, they

are about mobilising assets within communities, promoting equity and increasing people’s control over their health and lives.

### 3 Dream

As part of the 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

<sup>\*</sup> [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/402889/A\\_guide\\_to\\_community-centred\\_approaches\\_for\\_health\\_and\\_wellbeing\\_briefi\\_\\_\\_\\_.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/402889/A_guide_to_community-centred_approaches_for_health_and_wellbeing_briefi____.pdf)