Patients in Control:
Whose Health is it Anyway?

Key Themes
(South Region)

South East CSU commissioned as part of the Field Force programme by NHS England to provide support and expertise in the areas of Patients in Control (PiC)
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This Report

This summary report highlights the key priorities emerging from the Patients in Control Programme conducted in the South of England in 2014. This was commissioned as part of NHS England's Field Force Programme, to support CCGs and Area Teams in delivering more personalised healthcare.

The programme included the following activities:

- Online Survey of 933 patients with long-term health conditions and carers
- 75 in-depth telephone interviews with patients and carers
- 20 facilitated group workshops with specific CCGs in localities across the South region. Some of these workshops were patients/carers only, some were patients/carers with voluntary organisations and some were with CCG commissioners. Workshops took place in:
  - Dartford/Gravesham
  - Devon
  - Hastings
  - Thanet
  - West Kent
  - Guildford
  - South Kent Coast
- Service Co-design sessions in a number of CCGs, where patients and carers met with lead commissioners to co-design specific services (incl. Peer Support Models in West Kent and Brighton & Hove; a locality hub model in North West Surrey; a social prescribing model in Northern, Eastern & Western Devon and Torbay & South Devon, and; personalisation in care planning for diabetes patients in Crawley and Horsham & Mid Sussex)
- Case studies and video ethnographies of six patients

The programme has included input from patients and carers from across the South Region as well as voluntary, patient groups and CCGs.

This report sets out the priority themes which commissioners should focus on in order to best enable patient self management and suggests interventions which would be of value within each. The report also recommends some cross cutting areas which could enable self management in multiple themes.

The report concludes by assessing the programme itself highlighting parts of the process which have worked well and recommending ways in which similar programmes could be improved in the future.
Key Findings
Patients In Control; A Study of Self-Management Amongst Patients

Self management is very important to patients

- Patients consider it to be hugely important to have control over their own condition - as much as the condition allows. The majority of patients emphasise their desire for autonomy and independence.

  ‘the minute I lose independence is the minute that life is over’

- Most patients feel they have a good overall understanding of their condition with the majority feeling confident in this area. The weakest area is managing their overall emotional well-being. According to interviews, stress, anxiety and depression are frequently presenting in patients who suffer from physiological conditions. Emotional well-being is something that carers as well as patients struggle with, pushing it firmly into ‘priority’ territory.

- Patients were asked to rate their ‘instinctive’ level of satisfaction with the extent to which they A) understand their conditions, B) deal with pain or discomfort, C) manage their overall emotional well-being and D) maintain healthy behaviour such as diet and exercise. The strongest area overall is understanding the condition with the majority feeling confident in this area (although often they felt that they might have liked more information just after diagnosis. The weakest area is managing overall emotional well-being. It is important to note that we see a consistent link between pain and emotional ill-health, immobility and emotional ill-health and chronic conditions and emotional ill-health. Stress, anxiety and depression are frequently presenting in patients who suffer from physiological and mental health conditions.

Whilst the importance of self-management is rated a clear 10/10, level of satisfaction with current self-management is around 6/10.
Clinical System highlighted strongly as the most important area impacting on self-management

Data from the quantitative survey shows that even in the context of self-management, patients feel they would most benefit from improvements made to the clinical system itself (highlighted in chart below). To some extent this is a result of participants taking the opportunity to outline their frustrations with perceived problems that they have had with their care, rather than being fully relevant to self-management issues. However, it is worth remembering that these are the most important issues to patients and carers. Most patients with long-term health conditions have worked out a way to ‘get through’ their daily lives by managing their pain/condition in a way that works for them, at least to some extent.

Many patients and carers feel that they have worked this out for themselves mostly by ‘trial and error’ without having had as much help from ‘the system’ as they would have liked. This may not be the ‘perfect’ method of self management in all areas, but this may explain the relatively low importance placed on information and support by patients when compared to GP knowledge and access to specialist teams.

As this report outlines, the Patients in Control programme as a whole shows that the other specific areas on this chart can all provide significant help to patients’ and carers’ self-management while also improving perceptions of the clinical system and the general relationship between the patient and the NHS. This next slide discusses the clinical system, before identifying three priority themes for commissioners to focus on in aiding self-management.
NHS and GP surgeries are integral to self-management

Access to Specialist Teams

Nearly a third of patients feel that having immediate access to specialist teams is the most important area which would help them manage their condition more successfully. Carers and mental health patients particularly prioritise this area. Many patients feel that GPs could be more proactive when it comes to referring to specialists, and feel that if a particular problem is chronic, there should be a direct route of correspondence with the specialist team.

Early referral to specialist support would mean a more accurate care plan and would give the patient more confidence in it (including how patients and carers can self-manage). Seeing a specialist early on would outline the ‘best case’ and ‘worse case’ scenarios of their condition so they have a more accurate future forecast, aiding self-management.

GP Surgeries are integral to self-management

GP surgeries remain the most talked about clinical area by patients and remain the ‘logical’ and ‘trusted’ place to go for sufferers of long-term conditions to get the impetus and early confidence needed to successfully manage their own health in both the near- and long-term:

- The real point at which information and support-related needs are acute is immediately after diagnosis or ‘big’ news about a condition - many patients feel that the NHS could do better at this point in enabling self-management and improved wellbeing.
- GP surgeries are also the preferred place to build a Personal Care Plan, which is also seen as important for newly diagnosed sufferers of chronic conditions.

Acknowledging the importance of these areas is important to understanding patients and carers. In essence, surgeries and health services can ‘help patients to help themselves’ - they have key roles to play in each of the priority themes identified overleaf.
Priority Themes for Commissioners to aid Self-Management

All the research conducted within the Patients in Control Programme point to there being three priority areas where initiatives from commissioning groups would best enable effective self-management among patients:

1. **Personal Care Plans (PCPs)**
   Only a small number of patients claim to have a Personal Care Plan but they are the lynchpin of ‘system improvements’ going forward since they would enhance perceptions of: GP knowledge and accuracy, better and more constant access to specialist knowledge, continuity of care, and a more holistic approach to care and better preventative strategies - all the things perceived to be particularly important within the health system by patients.

2. **Education, Information and Training**
   Easily accessible information is rated as the most important theme (see slide 5) of those not so closely connected to the clinical system itself. When discussing the issue with patients however, it is clear that this is indelibly linked with education and training and are most usefully treated together. Most patients want access to as much detailed information as possible to help them understand their condition - ‘Information is Education’.

3. **Accessing emotional and peer support**
   There is currently a poor uptake of emotional support, mainly due to perceived inaccessibility and a lack of confidence among patients. Many commented on how they had not been offered emotional support or treatment at any point during the life-cycle of their condition. Many patients have developed their own coping mechanisms but nonetheless still point to their emotional wellbeing as the number one element of their lives that they are struggling with. Peer support is seen as very similar to emotional support as peers provide either an emotional crutch to rely on, or the education and assistance they can provide has emotional benefits. Support for carers is also crucial, especially for those looking after people with mental health issues.
Priority Theme 1: Personal Care Plans (PCPs)

- Only a small number of patients claim to have PCPs yet four in five (82%) agree that having one would help them manage their condition more successfully. Carers are particularly likely to say that PCPs should be a top priority.

- Ideally all clinical (automatically) and non-clinical practitioners (on request) should be able to have access to the PCP online although giving patients a paper version to carry with them when accessing healthcare (like the ‘red book’ given to new parents) may be a solid, cheaper alternative.

- Not positioned as ‘assessments’ of the patient but as supportive and empowering documents, which are felt by the patient to be ‘theirs’.

- Writing and ownership of PCPs should be in the hands of the patient as much as possible but produced with a professional (ideally promoted and administered through GP surgeries, but there is no requirement for the GP to be involved.

Perceived benefits of PCPs

- All information is logged in one place which makes patient feel cared for and secure
- Logging information also avoids repetition which frustrates patients and is a waste of time
- The PCP can set out ‘own personal idiosyncrasies’
- It is a ‘A living, working document’
- It is crucial for some illnesses such as epilepsy that the medication is correct
- It sets out holistic lifestyle goals rather than just fixing one ‘part’ of you
- It is very useful for carers in terms of medication doses
- A PCP would give the patient daily control, i.e. make it easy to manage and also monitor success which is likely to lead to increased success going forward

What should be in the PCP?

- Medical history
- Clear goals for patient from a clinical & social perspective
- Exercise and diet
- Clinical treatments/medications
- Non-clinical treatments (e.g. peer support groups, exercise, stress management/coping techniques)
- Allergies
- ‘Worst case’ scenarios
- Contact numbers
- Info on ALL types of relevant support available

‘Tailoring the personal care plan with emphasis on listening to the person, prompting them to do things for themselves and just doing the things that they can’t do’ CARER
Priority Theme 2: Information, Education and Training

- **Initial interactions with clinical professionals** are critical. At the point of diagnosis, it is crucial to be taken through information slowly and with understanding of individuals’ different reactions to receiving difficult news. Being given sufficient time to talk about the situation is therefore seen as very important to patients and carers.

- Given the time constraints under which GPs work, it might be beneficial to put newly diagnosed patients in touch with a volunteer patient or someone similar who is able to answer any questions or deal with any clarifications. They could also act as **emotional and peer support** should new patients start experiencing difficulties of a non-immediate medical nature.

- This might act to help the volunteer as well as the new patient in making them feel of value and able to help others.

- **Most patients would also like something written to take away.** This might be a **fact sheet, or 'pack'**, which acts as a starting point to finding out more about their condition. This should also form part of the same process by which they can find out about available support/volunteer groups which can help them manage their condition or deal with it emotionally. There was a feeling among some patients that this may also be available for some patients (Eg. cancer sufferers), but is certainly not available for all.

- **Signposting service within Surgeries.** This should be linked to finding support networks but should also include options for things like accessing exercise classes, dietary advice, information for carers and advice on non-clinical issues such as benefits. Any signposting carried about by GP surgeries (or indeed the NHS generally) would be a highly trusted resource.

<table>
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<th>When patients need information/education</th>
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<tr>
<td><strong>Before diagnosis:</strong></td>
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<tr>
<td>• Investigations and tests required and their purpose</td>
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<tr>
<td>• Reasons for referrals to specialists</td>
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<tr>
<td><strong>At the point of diagnosis</strong></td>
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<tr>
<td>• Causes, symptoms, what might happen to them in the future - some want great detail others do not</td>
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<tr>
<td>• What changes in symptoms to look out for</td>
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<tr>
<td>• What to do if condition changes</td>
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<tr>
<td><strong>Ongoing</strong></td>
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<tr>
<td>• When new medication is prescribed</td>
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<tr>
<td>• When new treatments or possible drug changes become available</td>
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<tr>
<td>• When attitudes change about how to treat conditions</td>
</tr>
<tr>
<td>• Information about team or individuals who are providing care</td>
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<tr>
<td>• Where to find out more or access further emotional or non-clinical support (see support section)</td>
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Priority Theme 2: Information, Education and Training  
(cont.)

- **Most patients feel that workshops** among other patients with similar conditions (and possibly run by volunteers who are suffering from similar conditions) would be extremely valuable, most probably around 6 to 8 weeks after diagnosis, so that the patient has been able to assess the difficulties they are experiencing. These sessions would provide training into understanding their condition and learning how to self-manage.

- **A few patients suffering from diabetes** spoke about how there are lots of different information sources (Diabetes UK, for example) but very few provide the depth of information required and most of this information does not come from a GP or health professional. There was also a calling for more follow-up information from a health professional, perhaps a year or so after diagnosis. One patient spoke about how they had taken part in an **Expert Diabetes course** (run privately) which they described as ‘brilliantly designed’ however they felt frustrated that their local CCG was not interested in taking it up.

- **Information provided proactively through ongoing support networks.** Information should never be seen in isolation - much of the support discussed earlier in this report could include components of information provision. CCGs could consider commissioning staff to provide regular visits to people with complex conditions and needs. This role could help patients navigate the different options available and advise on other issues.

- **More information on diet, nutrition and exercise.** This is seen as a key area where patients are lacking in knowledge - along with other preventative lifestyle improvements such as ‘socialisation’ and relaxation techniques. There is a feeling among many patients that this area is overlooked by the NHS.

- **Carers** of patients, particularly those caring for patients with mental health conditions, are desperate for more information on how to effectively manage these complex conditions and the mood swings and destruction that come with them. It is felt that there is not enough information or training for carers at home or for staff in care homes:
Priority Theme 3: Emotional and Peer Support

- Support at the point of diagnosis of any chronic condition is critical.

- There is currently a poor uptake of emotional support (talking therapies, and ‘one-to-one’ and group support from counsellors, clinical professionals or fellow sufferers), mainly due to perceived inaccessibility. Many patients commented on how they had not been offered emotional support or treatment at any point during the life-cycle of their condition.

- Emotional support is a crucial requirement for carers as well as patients (particularly for those looking after patients with mental illnesses) and is currently a type of support that is reportedly lacking. There are many cases where the families and carers of mental health patients actually suffer more than the patients themselves - particularly in cases of dementia sufferers where patients are often oblivious and/or numb to what is going on around them.

Barriers to accessing support:
- Lack of awareness of what is available
- Lack of confidence, exacerbated by their condition
- Lack of technological capability/access - harder to use online support forums, or find groups
- Financial constraints - some activities are expensive (esp. for those on low incomes - transport cost can limit patients
- Lack of suitable transport - public transport often unsuitable, with few flexible alternatives
Priority Theme 3: Emotional and Peer Support
GP surgery is critical to enabling support networks

- Critically important role in signposting and referring to relevant non-clinical services and support. Even though GPs and wider NHS may not be responsible for delivery of these services - they are the ‘logical’ and ‘trusted’ place to go for help and information
- This is predicated on being able to spend enough time with someone discussing appropriate forms of support and how to access them, and on their being flexible and open to discussing different options

‘[You need to] feel that they have taken time to get to know you and what would be best for you’

- Given the time constraints on GPs, a ‘care navigation’ or signposting role could be fulfilled by someone else at the surgery (or by someone/a team covering a number of surgeries) -

‘You just need someone to talk to and ask about these things. They don’t have to be the doctor’

- This person should have a detailed knowledge of the voluntary sector and the care/social care sector and be pro-active in updating their knowledge and informing existing patients of services.
- Whether this person is a full-time worker or a volunteer is not important and may depend to some degree on budget and the type of available volunteers. There may even be scope for enlisting other patients.
- Voluntary representatives report that GPs are often unwilling to signpost their services, perhaps because they do not want to be held account for services they cannot vouch for. Enlisting surgery support in signposting is vital to allowing voluntary services to be as effective as possible.
Priority Theme 3: Emotional and Peer Support

Need to cater for those who do not visit GP regularly

- While the GP surgery is a critical enabler in obtaining support, it should be noted that not everyone visits their GP regularly, some people with long-term conditions do not necessarily need regular visits to health professionals (indeed, carers may not visit at all). Therefore, an online directory of local services or information hubs at libraries, community centres etc. are beneficial - maybe maintained by patients or volunteers but promoted by the NHS.

- In many cases, these already exist so the greatest effort may be in getting this information to patients who may have become socially isolated or housebound, and to those who may be technologically unable to access information online.

‘There is a lot of support out there, but it is finding out about it that is the challenge. People just do not know where to look’

Promotion of Support Services & Networks

- Targeted Direct Mail & Email advertising to individuals identified as being at risk of social isolation or with particular conditions
- A broader mail out to retirees with handbook of useful organisations/websites
- Local Media Advertising
- Add-on to Health Help Now type system
- Local sponsorship by businesses (eg. supermarkets) to promote information services

Other ideas to help enable self-management through non-clinical support

(eg. peer support groups, exercise, stress management/coping techniques)

- Work on making specific services more accessible (e.g. community transport provision for people to get to support groups and other activities).
- Introduction of an administrative ‘umbrella’ function to help monitor and support non-clinical support providers.
- Look at supporting ICT-based services to provide befriending, peer support or in-home care (e.g. Skype based monitoring, similar to tele-monitoring).
- Support and signpost patients to more general exercise and well-being activities and classes, including yoga etc.
- Work to improve the quality of interaction between professionals and patients/carers in terms of communication joined-up thinking (work to develop thinking about symptoms/conditions in isolation and more about the overall ‘wellness’ of the individual.)
Contributing to Paid or Unpaid Work

It is clear from the discussion of the Priority Themes that the use of volunteer patients would be of huge benefit to other patients’ self-management routines. There are potential benefits to the volunteer as well, but also barriers to getting involved in such a way:

- Over half of surveyed respondents (58%) say that ‘contributing to paid or unpaid work’ would help them manage their condition more successfully, although very few (1%) say that this is the most important area of self-management going forward. Interestingly those who take part in volunteering say that it is an invaluable experience in terms of psychological well-being.

  ‘In retirement, I currently do lots of volunteering to help others and ward off depression’

- Only one in five long-term patients feel that it is not applicable to them in their situation. This does not mean that everyone else will proactively go out and look for ways to volunteer, but it does mean that there is a will to help others if the opportunity is right for the individual and they know about it.

  ‘I need to maintain healthy behaviours to combat late effects eg: regular exercise to help cope with chronic fatigue, and volunteering to try and overcome my condition’

- For those who don’t get involved in voluntary or paid work the barriers are as follows:
  - Mobility and transport issues
  - Mental health conditions mean that sometimes it is possible but at crisis times it is not possible

- Those who do get involved in this type of self-management are very positive about it; they see it as a lifeline:

  ‘It stops me sitting here brooding’ and ‘gives me a goal’

  ‘If I wasn’t working I don’t know what would happen… everyone should work if able’
Recommended Cross-Cutting Areas of Future Work

Looking across the priority themes there are five key areas which commissioners should consider going forward:

1. **Signposting services with GP surgeries.**
   GP surgeries are patients’ most trusted link to health services. However, most patients also complain at a sense of frustration with their GPs and the lack of ‘joined-up’ care they feel they receive. Developing signposting services which are accessible through GP surgeries (though not necessarily with any need to see the GP) would benefit patients in giving them clearer access to information, education, training and support networks, but would also benefit the NHS not only in terms of better enabling self management, but in increasing feelings among patient and carers that their health care is joined-up and reducing feelings of resentment towards GPs who many patients feel do not give them all the relevant information they need.

2. **Specific role to help long-term patients manage their condition**
   Patients want to be able to speak to a dedicated person who can discuss their non-clinical issues and help them to access support networks. For many patients an initial discussion in their GP surgery may be all they will need from this individual, for others the ability to make appointments for further discussion will be necessary. Who this person would be is less important, but this could be the nurse at the surgery, a paid individual or a volunteer. It is also likely that they may cover a number of surgeries.

3. **Volunteer Patients**
   Many patients report that they would be happy to lend their knowledge to other sufferers of similar conditions. Utilising these people would be of benefit to them and to other patients. Finding ways to encourage them to volunteer (maybe through a buddy scheme for example) would help to deal with many of the issues highlighted in this report while minimising resource spend required from employing.

4. **Carers**
   It should be remembered that carers in many cases are in even more need of emotional support than the patients, especially where mental health issues are concerned. They need to be given access to any signposting services and offered advice and support in similar ways to patients.

5. **Personal Care Plans**
   Although a priority theme in its own right, the Personal Care Plan can accomplish much of what is needed in terms of informing patients about their condition and helping them to realise the support they might need. In itself it is an enabler to further self management.
Evaluating the Process of the Programme
Engaging patients in the process is a win-win

- Across the project, feedback from participants was almost universally positive. In the workshops, there was no drop-off in terms of attendance between the first session and the third in each area and all of the 75 telephone interviewees were very receptive to the process and happy to be interviewed. There was only one patient who actually declined the opportunity of an interview at the point of being called. At the end of each interview patients were asked whether they were happy with the research, 100% said that they were.

- Participants have benefitted just from being part of the process with many reporting an increase in self confidence; some have even started looking for work or volunteering opportunities as a result, thus helping their own self management and others’.

- Local CCG involvement was rooted in the process in two ways: firstly, representatives facilitated sessions with patients/carers alone or in collaboration with voluntary organisations across localities; secondly, in the co-design of sessions with CCG commissioners. Voluntary groups have also been a strong part of the process (both in group work and accessing potential respondents for the survey) and links between them, the CCGs and patients can only have been enhanced through this programme.

- The co-design element of the programme (where patients and carers work with commissioners to share views and influence commissioning) reinforces what can be achieved through successful partnership work and patient engagement.

- It is this kind of partnership working which will help to engage patients in the future of health services, both collectively, in co-design of services, and individually in accessing the opportunities created through the co-designed interventions, including volunteer work which is important, not only to the individual, but also to many of the interventions that have been suggested in this report.

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‘The feedback has been extremely positive. Most of them would like to be more involved in the future’

‘It has been really interesting to hear how others respond to different situations and thinking, hey, I could do that myself!’

‘I haven’t been out on my own from my house for a year. Now I have been across the road to the shops - I feel I am on a high’

Some Early outcomes of Co-Design Sessions

- **Brighton & Hove CCG** is looking to build patient insight and co-design into all pathways

- **Devon CCGs** and patients were able to agree on a social prescribing model to promote to GPs

- **North West Surrey CCG** intends to include the local authority and voluntary organisations in any future co-design work

- **West Kent CCG** believe that co-design has changed the way it will commission services in the future.
Partnership working is critical to the success of workshops

- Partnership working between CCGs and Voluntary or community sector can add significant value to insight gathering activity because a wide variety of individuals can be accessed, targeting particular groups or health conditions where appropriate. This is very useful for a number of reasons:
  - It increases overall feelings that health commissioning is an inclusive process
  - It helps to ensure that the workshops are populated with people who have knowledge of NHS structures. While it is imperative to include ‘novice’ patients with little or no previous experience of patient involvement activity, it is vital that more ‘clued-up’ patients are included; they can make more strategic contributions. These people are also likely to be of great value at later stages of engagement where cost and other commissioning factors are of greater importance.
  - ‘Behind the scenes’ support for those patients is crucial in ensuring that the physical and emotional needs of participants are met throughout the insight gathering process. Voluntary sector organisations are experienced in providing such support and in addition, can bring with them a level of trust that can encourages participants not only to turn up in the first place, but to speak up and share their experiences openly, adding to the richness of the data.

- However, partnership working can be very time consuming, so too can working with patients with long-term conditions. In order to ensure any individual needs are met a great deal of patience and understanding is required to deal with inevitable delays or nuances of particular conditions. Thus if partnership working is to be developed further (as it should be), time for developing these partnerships needs to be factored in.

- It is important to recognise also that this partnership working does not necessarily need to be paramount in all stages of the project. While the workshops are best recruited in this way for the reasons discussed, the quantitative survey and its ensuing telephone interviews should be sourced, at least partially, through other methods (See next slide) - including the views of respondents not sourced through voluntary groups or CCGs is also critical to ensure a robust group of participants overall.

Participation Novices

A significant majority of all qualitative participants (workshops and telephone interviews) had not previously been involved in any patient participation activity before. This improves meaningful insight gathering activity because patients tend not to come with particular agendas. It also means that the consultation is more robust and not simply obtaining feedback from people who are already ‘in the system’.
Some other specific learning points for the running of the programme

Workshops

- Between 10 to 12 participants is the optimum group size for insight gathering. More people in a group does not mean better results. The number of groups/workshops should be dependent upon the geographic spread required and the different types of participant needed.
- Focussing sessions on particular themes is beneficial to the research as it allows sessions to go into far greater depth than if all workshops covered everything. There were some complaints from community groups and participants that they felt they were not able to go into their views on certain subjects, but this has to be balanced with ensuring sessions are of a suitable length for people with health conditions. Opportunities for a general discussion are ‘nice-to-haves’ within a workshop if possible, but it is important to ensure that this does not hinder the more focussed discussion. In reality, all participants were broadly very positive about the experience and potential leads to future volunteers were established. Thus ensuring in-depth discussion of themes outweighs the need for giving respondents the opportunity for general opinion-giving.

Survey/Interviews

- The survey was an excellent tool for generating quantitative data on opinions, but also led to a wealth of findings from the ensuing telephone interviews. A wide range of conditions were included and enough interviews conducted to ensure great depth of understanding. In future it is not necessary to increase the number of interviews but to attempt to build on the number of CCGs engaging fully with the process, thus ensuring a greater geographic spread of survey responses so the interviews can be better spread across the region.
- This process was augmented by a set of face-to-face interviews which provided written case studies and videos which the NHS can use at future events, to better personalise findings. Videos are an excellent way of making research seem more ‘real’ and can be utilised further in the future. There is no shortage of respondent who are prepared to participate if they feel it will be of value to the NHS and other patients (and carers) suffering from similar conditions.
Patients In Control; A Study of Self-management Amongst Patients

SECSU commissioned as part of the Field Force programme by NHS England to provide support and expertise in the areas of Patients in Control (PiC)

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