

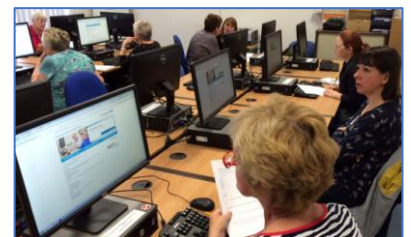
Report from a  
**Patient Consultation Meeting**  
22 June 2015



At our third patient consultation meeting 28 patients with inflammatory arthritis, osteoporosis and osteoarthritis from all our hospital departments across Bristol joined 10 senior clinicians and researchers to provide some specific help and advice, and to hear about some of the service changes that have happened and research which has taken place since the HIT began.

**The message emerged, loud and clear: patients welcome the opportunity to be involved in developing clinical services, teaching students and helping research. The way to make this happen is simple: “You only have to ask us!”**

At our Patients’ Day both old and new faces attended. It was especially good to have OA patients and professionals joining us. Time passed quickly on all of the morning sessions and we had to move on too soon to the next. It was exciting to be the first to try out the new BBJ website; even those who had never used a computer before were shown how to use one. Discussing self-help and ways to stay independent we discovered from each other the existence of activities within our local communities that are aimed at the elderly and less mobile. These ranged from line dancing and chair aerobics to knitting groups. Some involve more physical exercise than others but everyone agreed that the social contacts made were also very valuable. Hearing about the various research projects which are ongoing was very interesting and demonstrated that even small changes, which may appear insignificant, can make a big difference to a patient. Whilst enjoying the excellent lunch provided we collected questions to put to the professionals in our final session. These were dealt with clearly and succinctly - a testament to our medics and an excellent end to a very successful day.



**Edith Anderson & Pam Richards, Bristol Bones and Joints Patient Representatives**

## Our previous meetings:

1. In December 2012, the Bristol Bone and Joints Health Integration Team (it used to be called the Musculoskeletal HIT) held its first consultation meeting, attended by patients, researchers, managers and clinicians. It addressed the issue of “Involving patients and service users in the generation and transfer of knowledge in health care.” There was solid support for the notion of including patients as participants and partners in the identification of: research activity; the results of research that are relevant to patients in Bristol; and how those results are implemented and evaluated in clinical practice. “The challenge now”, concluded the organisers, “is to turn these aspirations into real activity on the ground.”



December 2012

2. In February 2014 there was a second full day consultation meeting with patients. Following an introduction setting the scene, there was active discussion and debate (supported by discussion group facilitators) about the strengths and weaknesses of current service provision, the potential for new research and innovation, and ways to increase participation in service development. At the end of the day patients considered how they can continue to be involved in HIT activities, and voted overwhelmingly to support patient involvement.



February 2014

## What is Bristol Bones and Joints Health Integration Team?

- Rheumatologists
- Nurses
- Physiotherapists
- Research Workers
- Orthopaedic Surgeons
- General Practitioners
- North Bristol NHS Trust  
Southmead, Frenchay,
- University Hospitals Bristol NHS Trust  
BRI, South Bristol
- Universities  
Bristol, West of England
- City Council  
Administration, Public Health

Working together to put research into practice and to work with patients to do more research.

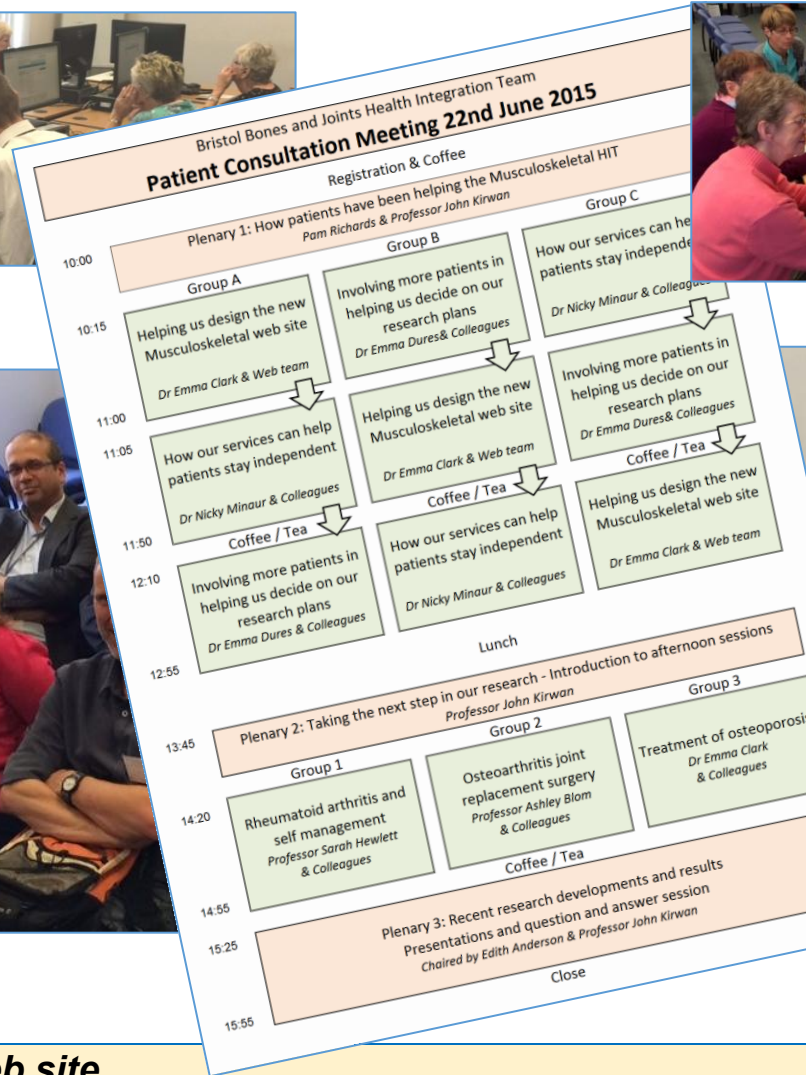
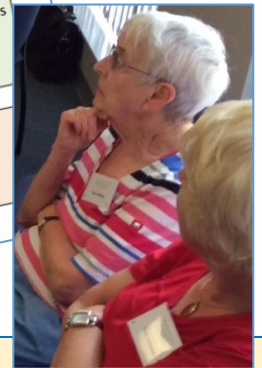
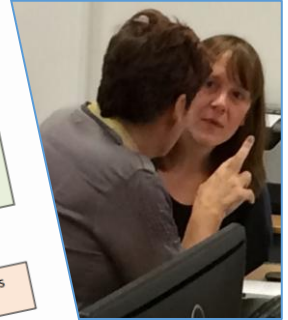
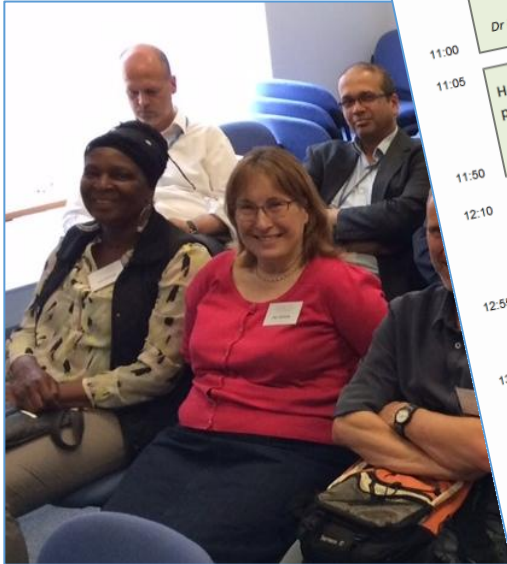
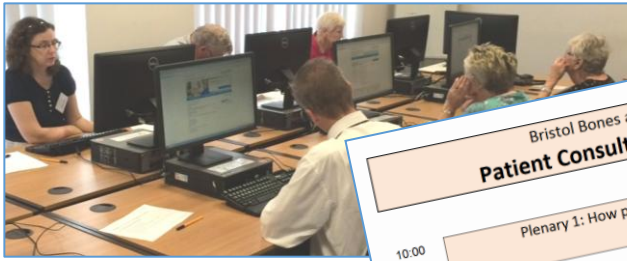


Avon and Wiltshire Mental Health Partnership NHS Trust  
Bristol Clinical Commissioning Group  
North Bristol NHS Trust  
North Somerset Clinical Commissioning Group  
South Gloucestershire Clinical Commissioning Group  
University Hospitals Bristol NHS Foundation Trust



## What we are working on:

- Osteoarthritis and Joint Replacement:**  
Primary care pathways and surgical care pathways
- Inflammatory Arthritis Pathway:**  
Stepped care: From intensive control to access when needed
- Osteoporosis & Fragility Fractures:**  
Primary & secondary fracture prevention pathways
- Self-management Support:**  
Access to evidence-based support
- Collaboration with Patients:**  
Help us understand what is important and prioritize
- Informatics:**  
Web-based information for patients and professionals



## This meeting:

### **Testing the new web site...**

Most people had used computers before (although for two people this was their first time!). In general most people thought they would definitely use the website for information and finding out about local services. People were pleased that the illustrations did not show patients with really severe and advanced disease. There were also some helpful points highlighting areas for improvement, particularly the need for a "return to home page" button, and more appropriate advice on exercise for people with arthritis - rock-climbing was felt to be far too strenuous!

### **How our services can help patients stay independent...**

**Information:** There is a need for accurate information at all stages of the pathway. This includes before being seen in secondary care, to enable an informed choice to be made of which service to choose. The information in leaflets, on the website and given by clinicians should agree and use the same language.

**Time:** Patients need more time with clinicians to discuss their needs. Patients need to be seen quickly when referred, especially within departments. There have been long waits for occupational therapy for example.

**Communication:** Patients need there to be open communication between departments. Too often clinicians are not aware of what has happened at previous appointments with other team members.

**Osteoarthritis (OA):** There was agreement that there was generally less support for people with osteoarthritis, except around the time of any surgery. There is a gap between diagnosis and surgery, with patients feeling unsupported. It was suggested that a video on the website could explain the benefits of physiotherapy for mild or moderate OA as patients may feel they are being fobbed off with physiotherapy after the diagnosis is made. Many people were not aware of the

ESCAPE knee pain programme, or the knee physio groups which run in various locations. It was not clear what self-management is supported by the musculoskeletal interface services (CATS and MATS), and people did not know how they fitted into the pathways for people with joint pain. *Osteoporosis (OP)*: Patients at NBT benefit from the group treatments for patients with osteoporosis and the hydrotherapy sessions, but these are not available for UHB patients. Patients value seeing their DEXA result, and the lay summary of the DEXA result and recommendations are now sent to all patients.

*Inflammatory arthritis (mostly rheumatoid arthritis, RA)*: There is much more support to self-manage for people with inflammatory arthritis, but there are differences between the services at UHB and NBT. At UHB, the direct access arrangements mean inflammatory arthritis patients can request an urgent clinic appointment with their consultant. At NBT, the telephone advice line is for all patients, and some people have found that it doesn't always work in that they are not always called back. A call to the NBT telephone advice line does not always result in a clinic appointment, as many things can be sorted out over the phone and with the help of the GP. NBT has the Living Well with Arthritis course over 7 weeks, delivered by the psychologist and patient partner. UHB has Prof Sarah Hewlett's Coping clinic. The physiotherapy department at NBT encourages self-referral back for inflammatory arthritis patients, while at UHB patients are referred by clinicians. There are several hydrotherapy groups for patients such as inflammatory arthritis and ankylosing spondylitis at NBT. The sessions are during normal working hours, making it hard for people to attend if they work full-time. The fitness group for inflammatory arthritis patients at NBT helps people increase their activities, while at UHB, people have done it themselves. People varied a lot in their approach to clinics. Some didn't prepare at all, while others take lists of things to discuss. Some people are used to setting and discussing goals, others not. Community services available in times of crisis, such as the rapid response team, can be hard to access. People did not know how to get extra help at home to avoid an admission.

## ***How our services can help patients stay independent...***

### **Changes suggested by the groups**

- Give hip & knee OA education much earlier, not just before surgery. A video could be useful, perhaps on the website.
- Physiotherapists could create a DVD of recommended exercises for the whole body and people could refer to it if they develop symptoms later. This could be instead of a referral back to physio.
- Occupational therapists could do group sessions to give general information rather than everyone waiting for an individual appointment.
- GP surgeries could identify on their website which GP in the practice is interested in MSK/ arthritis (if there is one). Some surgeries do this already. GPs often cannot help with specific arthritis problems, but need to understand about arthritis to give effective general care.
- Adverts could be taken out in the local free papers e.g. Bristol Observer, giving details of local services for people with joint problems. Posters could also be put in GP waiting rooms and the back of doors in public toilets.
- Changes required to leaflets to ensure consistency of language
- Increased length of consultancy sessions
- Improved waiting times for e.g. Occupational Therapy
- Improved communication between departments
- Provision of group treatments for people with osteoporosis at UHB
- Possibility of sharing resources eg UHB patients attending NBT-run sessions
- Fitness sessions in a community setting eg sports centre with hospital staff present
- Improved manning of telephone advice line (NBT)



- People valued continuity, especially seeing the same Consultant, but recognised how other team members such as specialist nurses have additional skills
- There should be the possibility of discussing wider issues and coping, not just focussing on immediate joint pain and medications in consultations with medical staff. Appropriate referrals (e.g. to a psychologist) and advice (e.g. on self-management) could then be made

### ***Involving more patients...***

**A personal approach is key:** Patients can feel unsure about what they have to contribute to teaching, research and patient/public involvement (PPI), and they might not think that a general invitation (e.g. a poster or leaflet in clinic) applies to them. Therefore a personal approach from someone in the healthcare team or someone from a patient support group is important.

We need to think about how we involve patients who are seen in primary care (e.g. information in GPs' surgeries). Also consider holding open information sessions and using established support groups to inform patients. Once patients have been invited to get involved, there needs to be a facility for them to leave their contact details. If patients register their interest, this should be followed up with a phone call or email.

**No prior experience of involvement needed:** Patients would like researchers and clinicians to be clear about how people are matched to research projects, teaching or the PPI panel. We need to emphasise that we do not require or expect patients to have any prior experience of teaching, research or PPI. What is needed is experience of living with a particular health condition. We should include examples of this, as it is not clear what it means in practice. For example, for a research project on fatigue in psoriatic arthritis, we would look for patients with the specific health condition (psoriatic arthritis) and the specific symptom (fatigue) to join the research team.

**Becoming involved:** There are important messages that might help patients decide whether to become involved:

- There are no obligations - if patients try teaching or research and decide that it is not for them, that is fine
- Let patients who are interested but unsure, shadow or observe an experienced patient partner in action
- Explain that involvement is not a lone experience (e.g. we have two patient partners in every research team, and teaching involves groups of patients)
- Clearly distinguish between teaching, research and PPI, as they are different roles which might suit different people

**Being involved:** Provide clear information at the outset.

This should include the time commitment, the level of involvement expected, and practicalities such as payment of travel expenses, and the location, frequency and timing of meetings. There can be a fear of the unknown, therefore

reassure patients that it is always fine to ask questions and there is no such thing as a stupid question. Clarify that the role of a patient partner in teaching, research or PPI is distinct from clinical care. Patients are involved as colleagues (i.e. patient partners). Their individual care will not be discussed, and everything that is said during meetings is confidential.

**Provide support for patient partners:** Patients who take part in teaching or research for the first time should be offered a meeting afterwards to see how they found it. This could be face-to-face or by phone. Thereafter, there should be an on-going point of contact.

**Highlight the value of research, teaching and PPI:** Let patients know why their involvement in research and teaching is valued, is important and makes a

- Invite + give permission (a personal approach from the healthcare team or a patient support group) but not in the waiting room or before an appointment
- Be clear about the time + commitment needed / level of involvement
- Information about practicalities (eg: travel expenses paid, location + timing of meetings)
- Emphasise → No research / teaching needed, your expertise is as a person with the health condition (give specific examples).
- Let patients know why research / teaching are important + valuable (include quotes from everyone who benefits - students, patients, clinicians).
- Support for patients who are involved -
  - point of contact (on-going)
  - de-brief after first few sessions of involvement
  - Shadow or observe a patient who is involved
  - patient involvement in pairs (eg. research) or group (eg. teaching)

difference. In written information, include quotes from everyone involved, such as patients, clinicians, and researchers.

We should put the North Bristol NHS Trust and University Hospitals Bristol NHS Trust videos about patient involvement onto a DVD as part of an information package.

**Clinicians and researchers need to communicate clearly:** Clinicians and researchers need to be aware of using jargon and acronyms. They need to make sure that they create an environment where patients feel comfortable asking them what they are talking about. It would be helpful to include brief bios of all the team so patients know who everyone is.

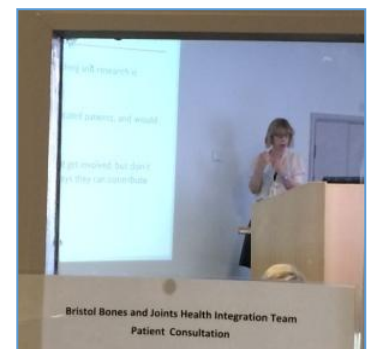
### ***Discussing osteoporosis...***

The afternoon disease specific session covered a wide range of areas. A few highlights were the lack of knowledge about falls services, the fact that no-one had been asked by their GP or pharmacist about side effects from osteoporosis medications, and some ideas for future research included improvement of risk assessment and looking at ways patients can self-assess what exercises are safe for them to do.

### ***Discussing osteoarthritis and joint replacement...***

We had a very lively discussion regarding all aspects of the pathway for patients with osteoarthritis, right from the original referral in primary care to post-operative management and follow up.

There was a feeling there was a delay in the diagnosis of arthritis from the first presentation of symptoms, to the actual localisation of the problem. There was also a delay in some cases from the diagnosis to the point of actual treatment in secondary care but in most instances this was satisfactory.



**Self-management:** The group felt that there needed to be more education about the condition and self management of the problem in primary care after the diagnosis was established on a similar pattern to that in inflammatory arthritis, in the form of activity modification, dietary advice, physiotherapy and hydrotherapy opportunities.

**Choice:** The general consensus was that the Choose and Book facility to see specialists in secondary care was a good option but there needed to be a lot of education surrounding the choice involved so that patients could make an informed decision. The group felt that the following things would be important for them to consider in making an informed choice: Success rate of the facility and operating surgeon; Access to early appointments; Care pathways in the respective hospitals and departments; Associated services, e.g. for patients with co-morbidities like inflammatory arthritis, kidney problems etc.; Surgeon experience; Complication rates, both hospital and surgeon specific. The actual prostheses being inserted were not known in the majority of cases, but the group did not feel this was a priority for them

**Outpatient (Pre-operative):** The group reported a positive experience overall in the outpatients department, and felt that this could be further enhanced by having images or models of the joints and prostheses in the clinic area. The education group sessions for hip and knee arthroplasty in the lead up to surgery were much valued by the group.

**Inpatient (Peri-operative):** Again, this was a positive experience, and was fairly consistent across the hospitals, with the group marginally preferring one hospital to the other depending on their other experiences as well. Most were happy with the duration of inpatient stay.

The single point echoed by the group was the need for a single point of contact post-discharge if they were to have problems.

**Follow-up (Post-op):** The group preferred to see the team for a face-to-face visit in the early post-operative period, e.g. at 6 weeks and 3 months, but then were happy to consider a virtual

appointment thereafter. They also felt that an open appointment to be reviewed by the team at short notice, would give a lot of reassurance to most patients.

Interestingly the negatives that were highlighted by the group were centred on transport, access to and from the hospital and the quality of food. There were individual negative experiences with some hospitals, but there was no consistent pattern.

The single most important recommendation coming for the group was to have a “Joined up” care right through primary and secondary care with links that communicate effectively and work as a team to ensure continuity of care for the patients. The most important factor that the group felt could lead to change was a “CAN DO” attitude among all the personnel involved.

### ***Discussing Self-management...***

A short presentation was given by Sarah Hewlett, Arthritis Research UK Professor of Rheumatology Nursing, in which self-management of arthritis was explained as including managing the condition (e.g. medications, appointments), managing the consequences (fluctuating pain, fatigue, disability) and managing the emotions associated with arthritis (frustration, feeling down or anxious). Further information was given by Dr Caroline Flurey on her research suggesting that men may have different support needs than women for learning how to self-manage, as they tend to access help in different ways (for example they sometimes get support from working alongside others, rather than talking face to face). Finally, some early results from an exercise to map out the different sorts of support for self-management provided across UBH and NBT were provided (for example group education programmes, 1-1 treatment sessions). During the useful discussions that followed from this, these suggestions and recommendations were raised by patients:

### **Information on available support for self-management:**

- Patients should routinely be given comprehensive information on what support is available to them and how they can access it
- Information about psychological / emotional support is needed (Trusts; as well as primary care where patients can self-refer to psychology teams such as LIFT or Positive Steps)
- This could be available in clinic, and on the new Bones and Joints Website
- There are GPs with a Special Interest (GPSIs) at most practices, and if patients knew who this was, they could ask to be seen by them for their arthritis

### **Access to support for self-management:**

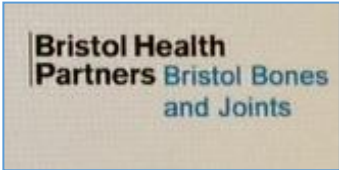
- All programmes or sessions should be available to patients from both Trusts, where possible
- Programmes should be of a similar standard or content
- Trusts might both run some programmes (e.g. hydrotherapy), or only one Trust might run it (e.g. fatigue support)
- There should be communication back to the patient’s usual rheumatology team/GP if a patient accesses a support programme from the other Trust
- Consideration should be given to the difficulty in accessing 9-5 services for people who are working
- Psychological support needs to be equal across Trusts – NBT has 6 sessions/week of a clinical psychologist; UHB has 1 session/week of a suitably trained nurse



### **Delivering support for self-management:**

- Where appropriate, patients could co-deliver some programmes, as in NBT Living Well programme
- Patient support groups, run by patients for patients, might be set up (as at Cossham)

- Some programmes might be specific to one disease (e.g. Osteoporosis education)
- Some programmes might be topic specific but across diseases (e.g. fatigue, or pain)
- Consider what label to use for psychological support clinics as this can be off-putting – UHB calls theirs a ‘Breathing Space’ clinic
- Online courses are easily accessible but might increase isolation or misunderstandings. One way might be to have these available in the clinic, with staff around in case of concerns or questions



**Support during routine consultations:**

- Patients should be actively encouraged to discuss support needs in routine consultations (eg given ‘permission’ to raise the issue by the clinician)
- Patients should be able to work with their clinician to set an agreed agenda at the start

**Evaluating the success of support for self-management:**

- Patients considered self-management would be successful if there was a sense of improved coping, self-confidence to manage, and quality of life

**A comment from Mike:** I attended wearing two hats - one as a Patient and Public Involvement (PPI) Facilitator and the other as a person with osteoarthritis. Wearing the first hat I sat in on the workshop on involving patients in deciding research plans. I enjoyed it so much and learned so much I sat in on it three times. In the afternoon I joined in with a group discussion about joint replacement surgery. Reassuringly, (my own knees will need replacing at some point) everyone seemed to have had a largely positive experience of surgery and a good outcome. For someone relatively new to PPI, the day provided an excellent example of how to do it well and what can be achieved when it is done well.

Organisation of the event strategically planned. Well done! Leaders had ability to manage and develop groups.

Catering and venue very nice indeed - a good choice.



Thoroughly enjoyable day - I felt that the public voice was heard.

You have the ingredients. Ensure you develop an 'I CAN ATTITUDE' that is willing to learn and listen and to make change possible. Thank you.

Next time:  
 \* Don't use plunger coffee and hot water dispensers. Tap ones easier to use.  
 \* Report on further developments in communication links with the local health service groups.  
 \* Help devise plans to implement change.

**Patients**

Edith Anderson  
 Brenda Ballard  
 Mike Bell  
 Lizzy Betts  
 Amanda Burston  
 Jenny Carter  
 Pat Clark  
 Debby Collett  
 Avis Edmunds

Enid Edwards  
 Anita Frith  
 Jo Gadd  
 Cora Hallett  
 Cath Harris  
 Gillian Hill  
 Julia Jarman  
 Jean Lawrence  
 Stephen Legge

Fiona MacKenzie  
 Alistair Moore  
 Valerie Moskovic  
 Sally Partington  
 Barry Powell  
 Pam Richards  
 Christine Silverthorne  
 Judith Sims  
 Caroline Swales  
 Louise Thorne

**Clinicians and researchers**

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 Prof Sarah Hewlett  
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