Report on the

Second Bristol Musculoskeletal Health

Integration Team Symposium

Saturday 15 February, 10.00 – 4.00, Education Centre, BRI

On 15th February 2014 patients from across Bristol joined researchers and clinicians in the second Bristol Musculoskeletal Health Integration Team Symposium. This was a full day consultation meeting with 34 patients who have rheumatoid arthritis or osteoporosis and fragility fractures – two key areas of work for the Musculoskeletal HIT. 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.

Bristol Health Partners

Bristol Health Partners is a collaboration between the city's three NHS trusts, three clinical commissioning groups, two universities and its local authority. We aim to maximise Bristol's health research, and to transform the understanding, prevention and treatment of key health problems in Bristol.

Health Integration Teams

As part of this mission we have established 14 Health Integration Teams (HITs) and are developing others. HITs are cross-organisational and interdisciplinary groups set up to harness research, innovation, education, healthcare and prevention strengths to improve health outcomes. They are tackling major health priorities by working together in a new integrated way.

Musculoskeletal HIT

The team focuses on three key areas: rheumatoid arthritis; osteoporosis & fragility fractures; and osteoarthritis & arthroplasty (joint replacement or repair). The latest Musculoskeletal HIT Patient Meeting concentrated on managing the long term problems of rheumatoid arthritis and dealing with osteoporosis to prevent fragility fractures.

Report on the Second Bristol Musculoskeletal Health Integration Team Symposium

Working together for better health!

Part 1: Overview and achievements of the symposium

This report provides detailed feedback from the Bristol Musculoskeletal Health Integration Team Symposium - ‘Working Together for Better health”, held on Saturday 15th February 2014 at the Education and Research Centre at University Hospitals Bristol NHS Foundation Trust. This was our second Symposium. The first Musculoskeletal - HIT Symposium (in December 2012) - although it was entitled “Involving patients and service users in the generation and transfer of knowledge in health care” - had just a few patients in attendance. It came up with plenty of ideas to be taken forward, but the concluding remarks of the organisers were that “The challenge now is to turn these aspirations into real activity on the ground.” This second Symposium is a direct response to that challenge. This time the two patient representatives on the HIT Board (Pam Richards and Edith Anderson), one of the HIT senior staff (Prof John Kirwan) and Bristol Health Partners’ adviser on patient engagement (Prof David Evans) were asked to focus on patient input to service development and new research opportunities.

The programme was designed to encourage and support patient contributions, and covered rheumatoid arthritis or osteoporosis and fragility fractures – two key areas of work for the Musculoskeletal HIT. Patients were invited to attend by the doctor or nurse that was looking after them, or through previous contacts with the research teams. They registered through our meeting secretary, were sent some simple information and full joining instructions. The meeting included refreshments, and lunch and travel expenses were reimbursed.

> “The challenge from our last Symposium was to turn its aspirations into real activity on the ground. This second Symposium is a direct response to that challenge.”

There were 34 patients in all (19 patients with experience of osteoporosis, the DXA service, or breaking a bone and 15 with experience of rheumatoid arthritis – although some patients had experience of both condition.) They came from different parts of Bristol and were under the care of both Hospital Trusts. Several were already advisers to some ongoing research projects, but for most this was their first opportunity to contribute in this way. Seven experienced research and clinical staff and the two patient HIT Board members acted as discussion group facilitators and helped with summing up and reporting back, and have contributed to the writing of this report.

In the morning discussions were centred on each condition separately and all the patients in a particular group had the same condition. They first focused on patients’ personal experience of their condition, how they had interacted with the health care system and how their investigations and treatment were handled - both the good and the bad. In subsequent sessions priorities for improvement and development were identified, and ways we might measure the quality of our clinical services explored. In the afternoon the discussion groups were reorganized with a mixture of patients in each group discussing in a more general way how to best maintain patient involvement in the musculoskeletal HIT. Before the close, a senior member of each of the research teams (Dr Emma Clark and Professor Sarah Hewlett) gave their overview of what had emerged from the ideas, Professor David Evans summed up the excellent way in which patients had been engaged in and contributed to the discussions, saying this was a model for future meetings, and Professor John Kirwan, who coordinated the day, thanked everyone involved for their enthusiastic and productive efforts.

The detailed report which follows provides much material for the Musculoskeletal HIT to work with, but here is how Professor Hewlett (rheumatoid arthritis) and Dr Clark (osteoporosis) summed up their take home messages:

Implementing self-management support for rheumatoid arthritis: Our patients have prioritized that not only should clinicians address the impact that inflammatory arthritis has on everyday life, but also that patients be given the confidence to broach these issues. They would like to work with us to train staff and patients in the skills needed to create an holistic and collaborative approach to treatment and self-management.

The clinical service for patients with rheumatoid arthritis: Patients greatly value the ability to have timely access to our specialised services and the integrated unit that means the multidisciplinary team are all together in one place. The patients would like to work with us on their service delivery priorities, which include patient information on current and new initiatives or care pathways, providing psychological support, developing further self-management training, and achieving an urgent appointment within 2 working days of using the helpline."

Implementing screening for osteoporosis: It was absolutely clear that patients want us to focus on screening for osteoporosis and identifying people at high risk of broken bones. We have the chance to take this forward through a series of grant applications we are submitting to fund some new research into screening high risk groups in primary and secondary care.

The clinical DXA service for osteoporosis: We will be working to implement our patients' recommendations on how to deliver a high quality DXA service: since this meeting we have already changed our service to ensure all patients receive a summary report of their DXA scan.

Based on the patient feedback, there are some clear messages about continuing engagement of patients in the work of the Musculoskeletal HIT:

- Patients want to learn more about their condition so they can understand and manage it better.
- Posters about the HIT, its function and its objectives should be on display, illustrating how patients are involved and how their views are valued.
- Occasional forums such as this one should be held, and more frequent smaller discussion afternoons related to individual projects.
- All patients should have the assurance that clinical services are not only what they receive but also what they can contribute to ensuring the service continues to evolve to meet the growing demand and needs of every person.
- A session by researchers on some of their current work could be incorporated into future forums.

- Where proposals made by patients are unworkable for various reasons, these should be explained at future feedback sessions.

Participants:

Organisers:
Prof John Kirwan
Prof David Evans
Pam Richards
Edith Anderson

Other presenters and facilitators:
Dr Emma Clark
Dr Emma Dures
Prof Sarah Hewlett
Dr Cecilia Mercieca
Dr Nicky Walsh

Patients
Susan Allen
Gill Baker
Jeanette Baldwin
James Bonehill
Margaret Bonehill
Janet Clarke
Darren Coombes
Helen Cooper
Christine Dockray
Mavis Eddy
Ann Fisher
Pat Goldsworthy
Catherine Harris
Christine Hayfield
Julian Hill
Sue Johnson

Patients
Mark Johnson
Stephen Legge
Eileen Massey
Michael Massey
Valerie Moskovic
Bob Noddings
Clive Rooke
Malcolm Scott
Margaret Scott
Janet Seamer
Christina Stiff
Caroline Swales
Lana Tavara
Agalgatti Vijaya
Mary Walsh
Thelma Webster

Assessment of the day by the organisers

Prof John Kirwan (Meeting organiser for the HIT): This was a very successful event! There were problems – Holding it at the weekend was more difficult that we expected for staff members to attend, and having the whole day was a challenge for some patients – although it provided a great opportunity for everyone to really understand the issues. Patients joined in the discussions very well – and the discussion facilitators (who were clinicians, researchers and patient partners from the HIT) did an excellent job. Support from experienced patient partners and researchers experienced in collaborating with patients was essential in the planning and execution of the day – now it's up to the HIT members to build on the rich fund of ideas and suggestions that are reported here.

Edith Anderson (Patient Partner for the HIT): From quite early on I was struck by how similar were patients' concerns in both the rheumatoid arthritis and osteoporosis groups. The negatives were: Access to consultants; Access to scans and tests; Parking- the BRI is especially difficult; Getting to and from the car parks, not just into the hospital but then to the actual department; Poor communication between hospitals both in and out of the area. The positives were: Physiotherapy; Hydrotherapy; Occupational therapy; - These all came in for special praise. There was an overwhelming feeling that at last patients are being listened to by the medical professionals. Ideas put forward were: Have consultants' clinics at GP practices; At outpatient clinics tell patients if there is going to be a delay – can go and get a drink, change their transport arrangements, etc; Let all patients know of the supporting societies; Have male-only groups as their needs can be different to those of women. Would patients come again? - An overwhelming "Yes!"

> "There was an overwhelming feeling that at last patients are being listened to by the medical professionals."

Pam Richards (Patient Partner for the HIT): It was a privilege and a pleasure to be involved in such a dynamic meeting. It felt like all who attended valued their access to health care and identified the areas where provision was lacking and could be improved. Our combined experiences and views felt like a powerful force. Acknowledging the best in the service we receive whilst voicing our concerns about the areas which make life more difficult. Every voice was heard – every person valued.

Prof David Evans (Organisation support from the BHP): I was really struck by the commitment and contributions from the many patient partners who attended. I believe that for a number in the osteoporosis group it was the first time they had attended a HIT meeting, and that it was the first time the rheumatoid arthritis and osteoporosis patients had met together. Given that this was such a new forum, people got down to work very quickly and very clearly expressed what the important issues were from patient perspectives. My sense is that patients both felt able to express their views and felt listened to by the researchers and clinicians present. I think the challenge going forward will be to synthesise and prioritise the many contributions into a do-able action list for the HIT to take forward. Crucially once action is taken, it will be important to feedback to the patient groups on what concrete actions, and in particular service improvements, have taken place in response to the contributions made on the day.

"It will be important to feedback to the patient groups on what concrete actions, and in particular service improvements, have taken place in response to the contributions made on the day."

Part 2: Detailed feedback for HIT members

MUSK@B HIT meeting 15th February 2014 Report

Two groups of people with rheumatoid arthritis (and a carer) debated the issues, facilitated by staff

Report by Cecilia Mercieca, Sarah Hewlett and Emma Dures

Session 1: Patients' perspective on the Bristol rheumatology service for rheumatoid arthritis and how to measure quality of care?

What patients expect from a rheumatology service.

- Better quality of life, less pain, less fatigue, improved function
- Rapid access to a specialised rheumatology service (someone who understands about RA); face to face with different health professionals, phone, patient support groups
- Listened to, reassured, treated as individuals
- Holistic treatment tailored to their specific needs. Interventions should include medication, physiotherapy, occupational therapy, psychological and social support.
- Be informed about their illness, medication, the rheumatology service, lifestyle changes and work. Information needs to be delivered in various forms; written, one-to-one, group, displayed in waiting area and online for the patients, their family and carers.
- Become confident in self managing their illness. Know which symptoms are due to RA and which are not and how to self manage.

How do patients feel they have had a useful consultation?

- They come out feeling it was worth attending
- They feel reassured
- They confident that the system is safe and responsive to their needs
- They feel informed about their own health and care
- They feel informed and given the opportunity to participate in research
- The role of their family has been recognized

- They have a feeling of holistic care being offered

What services do patients currently value?

- A dedicated outpatient unit and the close proximity of most of the facilities enabling a one stop shop approach; clinics, day case, bloodletting, specialist nurses, physiotherapy, occupational therapy, researchers. This facilitates communication among professionals, creates a welcoming environment, all are staff knowledgeable about rheumatology and the waiting area is adapted for rheumatology.
- Direct access
- Rapid advice line response - within 1 day. The unpredictability of RA is one of the main concerns of patients with RA. A flare can significantly knock back patients' confidence. This is when they need the multidisciplinary team support most.
- Medication support. Patients were generally very positive about taking medication particularly at the start of the RA. They feel that it makes a significant difference.
- The multidisciplinary team approach including psychological and self management support. For patients medication alone is not enough. Non pharmacological interventions may not be needed very early on until the medication starts working but patients need access as and when needed to non pharmacological interventions throughout their journey.
- Patient involvement initiatives
- National and public recognition of our service ex: best practice award
- The opportunity to participate in research and service development
- Staff dedication, reliability and efficiency
- Pre consultation self-administered questionnaires (as long as they are acted upon)

Unmet needs – what service improvements would patients like?

- Patients are unclear what we mean by pathway.
- They would like a map or plan of what might happen next (eg if this drug does not work)
- Education for themselves, their family and partners.
- Information on the services we offer should be provided and displayed
- Information on the leaflets available should be provided and displayed
- Patients feel there is lack of information for people with established RA. Contact time with health professionals is about 2-3 hours per year but patients have to live and manage their illness 365 days.
    - Need to be informed about new developments in RA and our service, treatments, patient initiatives and achievements.
- A patient calling the Direct Access service should be seen within 2 working days if the problem is severe, and 5 working days if it is moderate
- New referrals (ie not yet diagnosed) should be seen within 6 weeks
- More advice on general exercise, or maintaining exercises after physio has finished
- Become more confident in managing their condition
- Improved accessibility such as disabled parking, spacious waiting area, user friendly doors
- Waiting no more than 30 minutes for a clinic appointment (but understandable)

Suggested measurable quality standards

- Improved QoL (physical, mental and social)
- Reduction in the impact of fatigue, pain and disability (joint damage)
- Good patient experience. Patients should be listened to and reassured.
- Holistic treatment tailored to their specific needs. A written personal treatment plan.
- Interventions should include medication, physiotherapy, and occupational therapy, psychological and social support as needed.
- Support and education in self-management for patients, and also for carers should be provided

- Provided with updated information in writing about the services we offer, disease process, medication, lifestyle adjustments and support groups. Information on the leaflets available should be provided or displayed. This applies to both new and established RA.
- A patient calling the Direct Access service should be seen within 2 working days if the problem is severe, and 5 working days if it is moderate
- New referrals (ie not yet diagnosed) should be seen within 6 weeks
- Access to an advice line and replied to within 1 working day

Session 2: How can we best move our self-management research project forwards?

Self-management requires collaboration

- The clinical team can help, but the patient's individual determination, confidence and motivation are also important
- A guide for patients on 'finding your own way' could help
- Nurses, physios and OTs very supportive and well placed to support self-management ("I feel I can ask daft questions")
- Self-management might not be the right phrase (patients more familiar with adjusting and coping, and idea of doing as much as I can within my restrictions)
- This is a whole team approach, including some training for reception staff, who need to know the range of skills/opportunities the team can offer patients

Training for staff in consultations

- Clinicians should explain what patients can expect from a consultation (especially important for those who are newly diagnosed)
- Patients should be asked about their expectations
- Clinicians should ask patients what they wish to discuss at the start, not end of the consultation
- Clinicians must listen to patients, not dismiss their concerns, and must follow up on discussions
- Skills reflecting back to the patient are helpful (If I am understanding you correctly.......)
- The focus of the consultation should not only be on medication and symptoms, but should also explore impact (e.g. learning how to plan & structure the day, work, consequences of living alone)
- Important to explore patients' beliefs and concerns (e.g. reassure about advances in medication)
- It's important for patients not to feel rushed
- Clinicians should find out patients' personal priorities
- Clinicians should not dictate to patients - advice should be offered as suggestions and options, and clinicians should appreciate that patients decide whether the trade-off is worth it
- Physical and mental attitude and wellbeing affect each other in every way and a positive outlook is important for patients - if clinicians perceive low mood they should address it
- It's important that patients can ask all the questions that matter to them, but some patients can worry about being perceived as whinging - clinicians need to ensure that patients feel comfortable talking about the wider impact of RA
- Clinicians could have a framework to guide the consultation – how to start, how to finish off
- Use patients to help train staff
- After training in consultation skills, use lay observers to appraise; or an anonymous questionnaire for patients for all consultations in one week
- Consultations carried out this way may take longer, esp if include self-management – assess cost

Training for patients in consultations:

- Patients should think about what they want to discuss before the consultation: provide a template 'prompt' sheet at reception desk, with some pre-determined categories and some free text ones
- Patients should come out of clinic with a list of decisions/actions – perhaps fill in on reverse of the prompt sheet described above
- Prompt sheet could be brought back to next appointment to review
- Offer training to patients on best use of consultations (see self-management below)
- Consider asking expert patients to talk to other patients in the waiting room (Ambassadors)
- Patients could ask to take their questionnaires in to the appointment (eg HAQ) to use for discussion
-

Self-management: Patients need support for making behaviour changes

- Reassurance from the clinician can help build confidence (people can lose confidence when they are given a diagnosis, and/or experience a bad flare)
- Patients will be ready to make behaviour changes and receptive at different points in their lives (recognition that everybody adjusts differently); learning to manage everyday activities requires time, therefore timing of support cannot be fixed: there should be an open-door policy
- Clinicians and patients should set small, achievable goals as small changes can make a difference
- Important to run a self-management programme. Consider using co-leaders: expert patient alongside expert professional
- Consider information in an initial pack for newly diagnosed patients: how to use consultation, being an equal partner, services available, sources of support, list of booklets they could request
- Self-management support should be based on evidence of how to help change behaviours, such as goal-setting and homework; should be interactive with the patient as partner (not told what to do)

Information needed about available support

- The clinical team should provide information about patient groups and other sources of support such as NRAS
- Discussion groups with other patients can give people ideas, practical examples and reassurance
- Inform patients about the different skills of the MDT and how to access their services when needed
- Try a computer screen running in clinic with useful websites and tips etc

Summary of patient priorities for supporting self-management:

- Holistic care, including self-management and psychological support is the remit of the whole team
- Teams need the skills to identify (ask about) and then support patient's emotional and psychological needs
- Teams need the skills to facilitate self-management by patients. This includes 1-1 consultation skills, and group programmes (which might be co-led between patient and professional leaders)
- Self-management support should be based on evidence of how to help change behaviours, such as goal-setting and homework; it should be interactive with the patient as partner (not just told what to do)
- To become effective self-managers, patients need the skills and confidence to collaborate with the team

OSTEOPOROSIS, DXA SERVICE AND FRAGILITY FRACTURES

The Sticky Note Exercises!

SESSION 1: SUMMARY OF AREAS OF IMPORTANCE FOR PATIENTS

Summary of verbal discussion (in no particular order)

-lack of information in outpatients
-lack of explanations
-cost – does this drive service? It's a worry
-difficulty searching for information on-line
-lack of info with DXA scan – some people get results, some don't, some get information leaflets
-issue with appointments
-haven't heard of FLS
-early access for high risk groups
-lack of co-ordination of systems, appointments, communication
-guidance on good quality information online
-emotional support needed
-excellent service from osteoporosis nurse
-helpful staff
-very good GP
-NOS involvement in osteoporosis clinic (UHBristol)
-excellent rehabilitation, physio and hydrotherapy
-too many gatekeepers to the service – prevents access
-good communication between doctors, GPs and registrars
-transport and parking
-timely access to information
-screening of high risk groups
-DXA should be automatic
-postcode lottery
-rehabilitation
-clarification of results
-want details of DXA on the NHS
-OT access
-group support
-individualised treatments
-good info re exercise
-involve family
-GP time
-listen, and time
-primary and secondary education
-steroids causing osteoporosis
-how long on bisphosphonates
-DXAs delayed
-how to get referred for a DXA
-access to NHS DXA]-
-access to DXA
-money not spent on DXAs
-issues of free DXA
-Southmead appalling
-holistic, not just pharma
-GP access timely
-trust, understanding and quality
-disparity between North and South Bristol
-fear of leaving private sector
-inpatient facilities – pressure relieving mattresses
-regular review
-free screening
-free hydro
-right to access consultant
-free parking
-no link between North and South Bristol
-time with GPs
-joined up approach
-financial support for taxis
-don't be told what drugs cost
-GP not mentioned DXA
-concern re bisphosphonates and automatic prescription
-communication between hospitals
-delayed or no services
-concern re strontium withdrawl

-let people know how long they will wait
-shared health information
-how to get referred for a DXA
-GP time
-primary and secondary education

Sticky notes related to diagnosis (in no particular order)

-diagnosis of osteoporosis
-screening should be automatic if high risk e.g. steroids
-earlier access to scans
-should be able to ask for DXA privately
-shouldn't have to pay for DXA
-?for those at risk – is there any way they could be identified
-not everyone goes to an osteoporosis clinic
-have to break a bone before diagnosis
-earlier diagnosis
-no clear diagnosis
-initial diagnosis of osteoporosis

Sticky notes related to information (in no particular order)

-lack of clear information
-getting information about disease and support into the NHS system
-scary – information given badly
-give NOS leaflet with DXA results
-pharmaceutical company information is nonsense and delivery arrangements poor
-to find as many contacts as possible within Bristol to obtain and deliver osteoporosis information
-NOS not publicised at the BRI or GPs
-GPs should print information leaflets re:NOS and medication during consultation
-people want to know what's going wrong with their body and what's available
-how are treatment effectiveness measured – is it just cost?
-confusion about calcium and vitamin D level tests e.g. blood, too much calcium
-possible withdrawl of strontium
-what can be done to strengthen cartilage and stop crystals or bony outgrowths causing stiffness, pain and inflammation
-is there medication that gets rid of bone and allows new bone growth without side-effects or damage to other parts of the body
-typo's cause confusions
-lack of good explanations re:change of treatment – poor confidence in change
-is there someone I can talk to about treatment info – what is best for me?
-are there any new drugs on the market without side effects? E.g. SCOOP study?
-candida albicans attacks immune system – does this affect osteoporosis?
-information to patients
-good information for my condition
-Consultants in GP practices
-different services at different hospitals
-time with staff
-DXA access
-specialist knowledge

Sticky notes related to liaison/communication links (in no particular order)

-appointments difficult to make follow up appointments
-systems don't seem to work
-poor discharge planning: OT assessment done in hospital not at home
-failure to understand implications of multiple health problems
-discharge needs improvement from assessment onwards
-no follow-up consultation after DXA scan – just told to take alendronic acid plus calcium/vit D!
-need more physios – need to work 24/7
-physios need to be more available in hospital post-surgery
-not everyone gets DXA results
-DXA results given – some not for a year!
-lack of communication between health care professionals
-GP knowledge and awareness
-proper training for support staff
-disjointed

Sticky notes related to emotional support (in no particular order)

-in hospital: lack of care and compassion post-surgery can be emotional and traumatic – even one bad comment by e.g. nurses
-emotionally low post-surgery and lack of care and compassion in hospital
-not always treated as a 'whole-person' with other conditions
-lack of support for patients
-its difficult for patients in outpatients

Sticky notes related to positive things (in no particular order)

-better follow-up compared to the past
-hydro group great but not everyone knows about it
-hydro group 6 week course good
-brilliant hydro and physio
-hydro great
-Prof Tobias
-apart from diagnosis, everything else has been good
-waiting times for surgery are shorter
-once you're in the system it's great
-some can get double appointments with GPs
-Frenchay – morphine relieved pain
-good DXA experience
-some get regular appointments because of hormonal treatments
-good GP and Fracture Liaison Clinic
-good consultant
-good liaison nurses
-Fracture Liaison Nurses – not everyone knows
-fantastic informative nurses
-NOS helpline with nurse
-NOS information strand in BRI
-volunteer helpline
-attractive leaflets in physio areas
-doctors far more human!
-consultants so good when you get to see them
-knowledge of staff
-access to injections
-fracture liaison nurse
-vertebroplasty for fractures
-waiting times in outpatients
-physio
-physio excellent!
-Shane's lovely

SESSION 2: PRIORITIZATION EXERCISE

1. SCREENING
-high risk groups
-GP education of importance

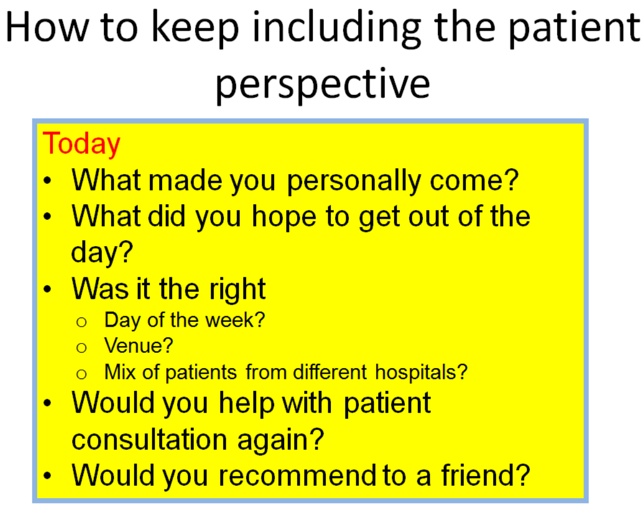
2. ACCESS TO INFORMATION
-at all stages
-at diagnosis
-ability to get more information
-*when* is important
-information on prevention for family members
-information on self-management
-treatment options
-scan results to patients
-website for service access

3. GP AWARENESS
-on how to get DXA scans
-on screening
-on treatments
-better shared information across services
-GP is key – information starts here

SESSION 2: QUALITY INDICATORS FOR A DXA SERVICE

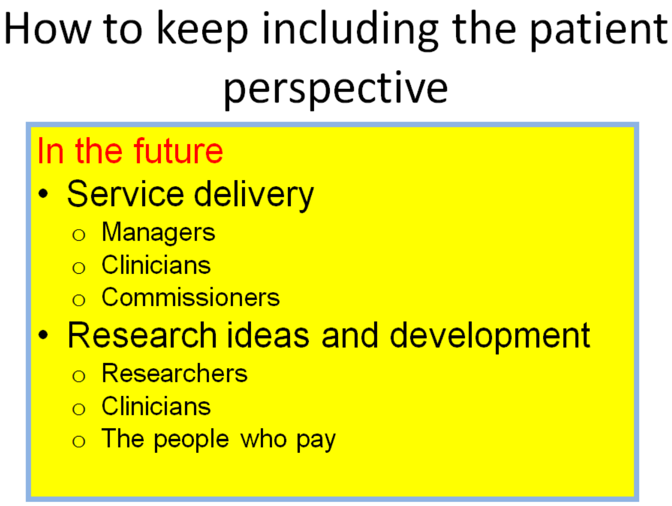
1. Full information leaflet in advance of scan e.g. with appointment letter detailing what it entails
2. NOS leaflet with all results
3. Provide report to all patients
4. Ensure there is a clear comparison with previous scans if carried out
5. Opportunity to discuss results post-scan – helpline etc
6. Waiting no longer than 12 weeks between fracture and scan

SESSION 3: THE FUTURE



How to keep including the patient perspective

Today
- What made you personally come?
- What did you hope to get out of the day?
- Was it the right
  - Day of the week?
  - Venue?
  - Mix of patients from different hospitals?
- Would you help with patient consultation again?
- Would you recommend to a friend?



How to keep including the patient perspective

In the future
- Service delivery
  - Managers
  - Clinicians
  - Commissioners
- Research ideas and development
  - Researchers
  - Clinicians
  - The people who pay

<u>Why did you come?</u>
-to help
-to support the NHS
-to get information about medication
-to find out more information
-curiosity
-'not a gripe' but to give feedback
-interest, and to gain knowledge
-to help – interesting
-the need to emphasize good and bad practice
-to give something back

<u>What did you want to get out of it?</u>
-service improvement
-information

<u>Was it the right day of the week etc?</u>
-Saturday is a good day
-venue was chilly downstairs
-good mix of topics
-no gluten free meals
-would definitely recommend this to a friend

<u>How can we keep patient involvement within the HIT?</u>
-need future meetings
-need to develop an ongoing relationship
-need to think of ways of getting more patients to take part
-shared meetings with patients
-why aren't commissioners here today?
-we (patients) could ask the fundamental questions
-want direct face to face meetings with commissioners
-once or twice a year maximum

Feedback on the conduct of the day

- What went well? What did you enjoy?

Honesty and openness of participants	Networking, sharing ideas
Positive thing – interaction of ideas. Improvements – None – it was very well organised and put into practice.	Good mix of patients willing to share experience and ideas for service improvement.
I enjoyed meeting other patients.	Good mix of people, well facilitated groups, good presentation, good feedback.
Discussion groups. Consultation with Consultants.	The focus on both delivery and research.
Enthusiastically driven. Time to discuss various issues.	Meeting with people. Meeting with research team. Hearing other people's experiences.

More Sticky Notes!

Group discussions, good speakers.	Being able to speak openly to improve an already excellent service.
Group discussions. Sharing information. Include research programmes.	Meeting other patients. Sharing experiences.
Interaction.	People listening, brain storming.
Group interaction and discussion.	I enjoyed hearing other people's experiences.
Good meeting up with other people's views and opinions.	Meeting like minded people. Having information not known before.
The whole meeting.	A good interactive programme. Small relevant discussion groups.
Meeting others in similar circumstances.	An opportunity to contribute. Expenses reimbursed on the day.
Thoughtful and open input from patients.	Lunch!
Feeling heard	Lunch!
Very well organised and informative.	

- What could we do next time to make a meeting like this even better?

Heating and more varied lunch.	Have managers, commissioners and other professionals eg O.T. present.
Not be left outside in the rain.	Food – have dietary options.
Access. Dietary needs taken care of. Feedback.	Have heating on in lower level.
Include clinicians, GPs etc in the day. Focus specifically on drugs and other treatments for osteoporosis.	Communication went well, enjoyed networking, next time – more info on drugs and alternative medicine.
Invite GP, discuss research.	Have managers, commissioners etc here.
Invite GPs and researchers.	Involve some of the managers more.
Some information about future research in this field would be helpful.	Consider lunch for people who don't eat wheat and gluten or processed food.
Involving admin staff, managers and commissioners.	Include next time could be medical treatments and research.
More advance notice of the date, time etc.	I would like more info on vertebral fractures.
Hearing about what research is being done – new drugs on the horizon would be good at future meetings.	It was super to be able to ask experts for info and to receive it! Great to talk with fellow sufferers. More experts!
Hope some of the suggestions are followed through if funding allows.	Enjoyed meeting other people with RA & OP and exchanging experiences.
Clarity for patients on how they could get involved in the HIT.	Not sure… Day has gone very smoothly –possibly limit questions to allow more time for answers.
More lunch!	

Part 3: Appendix – Some materials from the symposium

Introductory presentation

Bristol Musculoskeletal Health Integration Team

Patient Meeting

Saturday 15 February 2014

Welcome to the meeting!

- Part 1 – Improving the way we look after patients
- Part 2 – Doing good research to find new ways to help patients
- Part 3 – Making sure we keep patients involved in our work

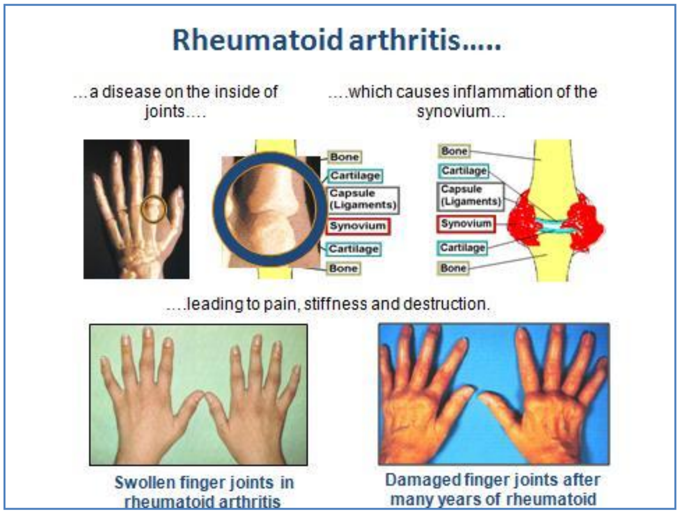
Bristol Musculoskeletal Health Integration Team

- Rheumatologists
- Nurses
- Physiotherapists
- Research Workers
- Orthopaedic Surgeons
- General Practitioners

- Hospitals
  - Southmead, Frenchay, 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.

What is rheumatoid arthritis?



Rheumatoid arthritis.....

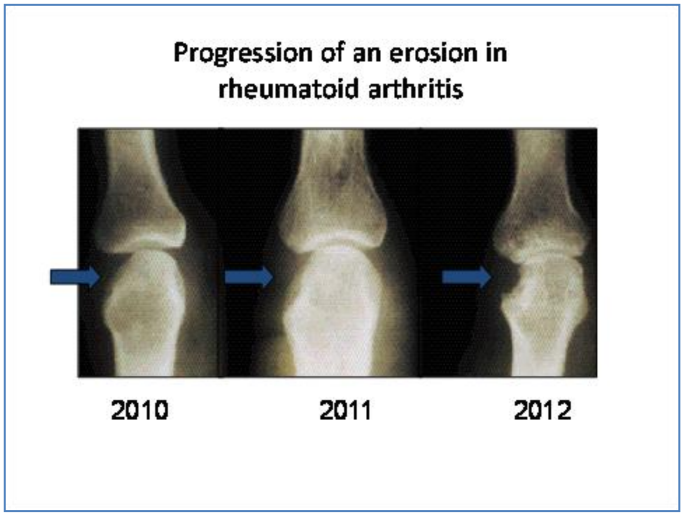
...a disease on the inside of joints....

....which causes inflammation of the synovium...

....leading to pain, stiffness and destruction.

Swollen finger joints in rheumatoid arthritis

Damaged finger joints after many years of rheumatoid

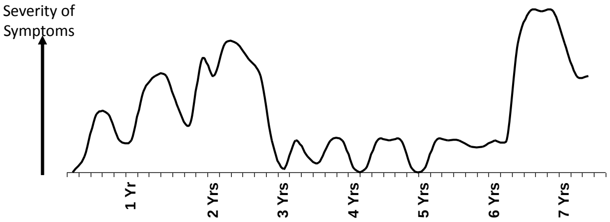


Progression of an erosion in rheumatoid arthritis

Symptoms in the words of a patient

HTV West Broadcast 1995

Patient BT
Clinical Inflammation



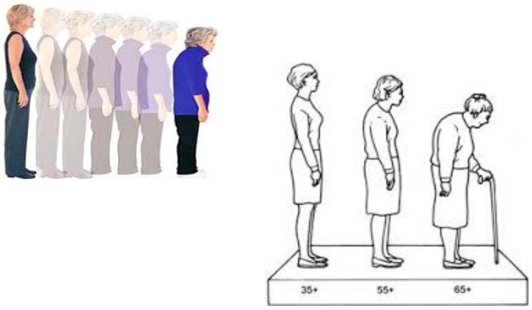
So…

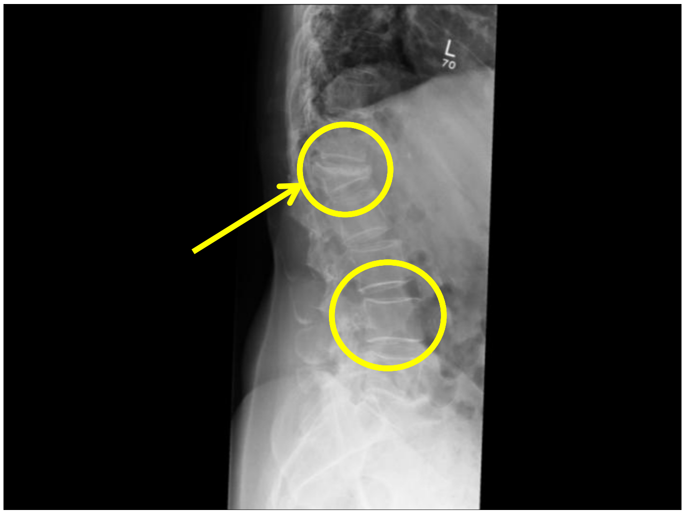
- Rheumatoid arthritis (RA) involves
  - Inflammation inside joints
  - Destruction of joints
- About 1 person in 100 will get RA

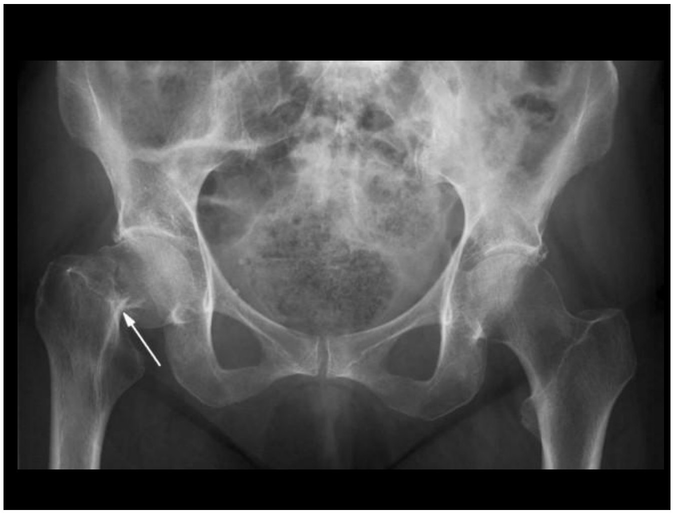
Treatment of rheumatoid arthritis

- Keep active
- Painkillers
- Anti-inflammatories
- Disease modifying drugs (e.g. Methotrexate)
- Glucocorticoids (‘Steroids’)
- Biological treaments (e.g. Anti-TNF)

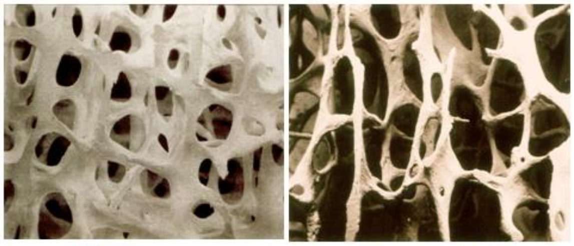
Osteoporosis







Osteoporosis – ‘thin bones’



Healthy bone

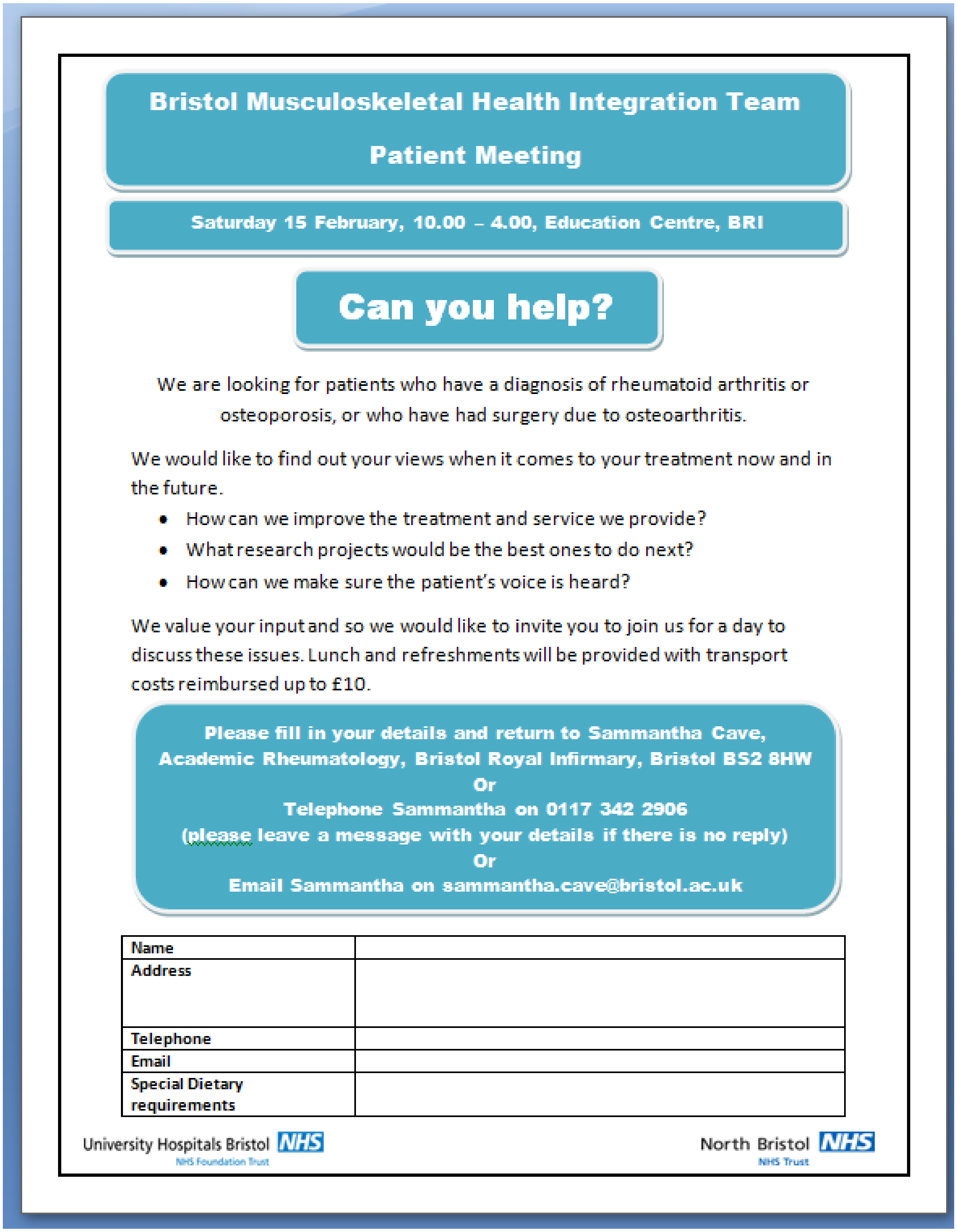
Osteoporotic bone

A DXA Scanner

Treatment of osteoporosis

- Keep active
- Bisphosphonates (e.g. Alendronate with Calcium and Vitamin D)
- Biological treaments (e.g. Denosumab)
- Hormones (e.g. Teriparatide)

Invitation



Bristol Musculoskeletal Health Integration Team

Patient Meeting

Saturday 15 February, 10.00 – 4.00, Education Centre, BRI

Can you help?

We are looking for patients who have a diagnosis of rheumatoid arthritis or osteoporosis, or who have had surgery due to osteoarthritis.

We would like to find out your views when it comes to your treatment now and in the future.

- How can we improve the treatment and service we provide?
- What research projects would be the best ones to do next?
- How can we make sure the patient's voice is heard?

We value your input and so we would like to invite you to join us for a day to discuss these issues. Lunch and refreshments will be provided with transport costs reimbursed up to £10.

Please fill in your details and return to Sammantha Cave,
Academic Rheumatology, Bristol Royal Infirmary, Bristol BS2 8HW
Or
Telephone Sammantha on 0117 342 2906
(please leave a message with your details if there is no reply)
Or
Email Sammantha on sammantha.cave@bristol.ac.uk

Name	
Address	
Telephone	
Email	
Special Dietary requirements	

University Hospitals Bristol NHS
NHS Foundation Trust

North Bristol NHS
NHS Trust

Joining instruction

Bristol Musculoskeletal Health Integration Team
Patient Meeting

Joining instructions

Thank you for volunteering to come to our meeting on

Saturday 15 February 2014, 10.00 – 4.00.

Your contribution is really valued and we appreciate you taking the time to attend.

The meeting will take place at the UBHT Education Centre, Upper Maudlin St, Bristol.

http://www.uhbristol.nhs.uk/files/nhs-ubht/ubht_map.pdf - Building No 6

We will be discussing your views about your treatment now and in the future focusing on the following areas:

- How can we improve our service and introduce new treatments?
- How can we best move our research projects forward?
- How can we make sure patients' voices are heard?

We will provide lunch and refreshments throughout the day.

We will reimburse your transport costs up to a value of £10. Where possible, please provide receipts.

Car parking options:

http://en.parkopedia.co.uk/parking/bristol/

We have 3 park and ride locations:

http://www.travelwest.info/parkandride

Bus timetables

http://www.firstgroup.com/ukbus/bristol_bath/journey_planning/timetables/timetable.php?day=1&source_id=2&service=8/9&routeid=8743941&operator=3&source=sp

If there is anything further you need to know please contact **Sammantha Cave**:

Email - sammantha.cave@bristol.ac.uk

Tel – 0117 342 2906 – please leave message if there is no reply

We look forward to meeting you