



Patient Public and Practitioner Partnerships within Imaging and Radiotherapy: Guiding Principles

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Introduction

The NHS Five Year Forward View¹ lays out its vision for a shift in power to patients and the public:

"One of the great strengths of this country is that we have an NHS that – at its best - is 'of the people, by the people and for the people'...we need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services."

In response to this new agenda, the Society and College of Radiographers (SCoR) held a one-day workshop in 2017 to understand how best to engage patients and public as stakeholders within imaging and radiotherapy practice. A key outcome from the workshop was an agreement that true partnership needs a shift in SCoR strategy.

The 'patient voice' is therefore now a central feature of the 2018-20 Strategy of the Society and College of Radiographers². Strategic priorities will "Ensure the Patient Voice is Integral" (Society) and "Be Informed by the Voice of the Patient" (College).

However, in practice, patient and public partnership working is often implicit rather than explicit; a clear direction is vital for a shared overall vision. Everyone must be involved, thus embracing different perspectives in a systematic public partnership and this approach must be sustainable.

Task and finish group

In order to press forward the patient and public partnership agenda within radiography practice, a small task and finish group was convened. This comprised patients, practitioners, researchers, educationalists and SCoR officers. The group's remit was to investigate further the requirements and changes needed to ensure that the SCoR priorities relating to the centrality of the patient voice will become embedded throughout the organisation.

The aim of this document and how it should be used

In response to the remit, the task and finish group have co-created this set of guiding principles for Patient, Public and Practitioner Partnership (PPPP), which is intended for use by all those with a stake in the quality of radiography practice.

Whilst we are mindful of the pressured working environments within which today's imaging and radiotherapy staff work, we believe that in following these guiding principles practitioners may begin to alleviate such pressures by establishing conditions under which high patient (and staff) satisfaction can flourish.

This document is divided into four sections, each related to key areas of radiography practice: Service Delivery; Service Development; Education; and Research. Within each section are a set of core values which are expanded upon using authentic patient stories to illustrate the impact such values have on patients, carers and the public. These stories have been garnered from a number of sources including: statements from patient members of the PPPP task and finish group, quotes from research participants, and stories from CareOpinion.org.uk. It also includes examples of good practice and guidance which can be used by a range of stakeholders wanting to develop PPPP within their own areas of work.

In keeping with the notion of patient engagement, core values are written in the patient voice.

Section 1: Service Delivery for Person-Centred Care

Core values

"During my imaging or therapy procedure I would like it if you could"...

1. Introduce yourself and tell me your role in the management of my care:

"Tell me your name using 'Hello my name is... and I am a ...' and then tell me your role and what you want with me today because we are then on an even footing"

"The radiographer asked me what I would like to be called – it was a nice touch"

"I might think you are a nurse or a doctor because the uniforms can be confusing. Please correct me so that I know you are a radiographer"

2. Treat me as an individual and explain the purpose of the procedure with specific reference to the management of my particular case:

"I heard the radiographer referring to me as the "next chest" and it made me feel inhuman, I worried about how I would be treated in the x-ray room"

"I had an MRI scan but nobody explained why. The radiographer appeared to act as though she was just obeying instructions, she did not come across as if she played a part in my clinical pathway. This made her seem like a technician rather than a professional."

"I had a cannula put in my arm, but nobody explained why. I was in the tunnel but my query was ignored because she had her written instructions."

3. Find out what is important to me:

"I would like you to find out what is important to me so that you can help me to make the best decisions for me. Listen to me and address my concerns then talk to me in a language I understand. Don't use jargon but please don't patronise me. Take time to adapt your communication if required"

4. Provide me with high quality patient information and check I am informed enough to consent to proceed:

"[I] had lots of queries about breast screening when I got my first letter. I'd heard so many negative stories before I went and in fact it was a positive experience for me, with screening staff providing lots of info. Must say this would have been better **before** I arrived for the screening!"

"Please don't assume I will not understand. Nobody told me that the CT used Ionising Radiation I would have like to have known"

5. Ensure that I understand your role and make me feel confident and safe in your care:

"It may not matter to me that you are a radiographer rather than a nurse but I need to know that you are skilled at what you do, that the equipment you use is up to the job, and that I can have complete confidence and feel safe in your care. Show me that you know what you are doing and that I can trust you"

"I was extremely apprehensive about the MRI scan fearing that I would not be able to cope with the very claustrophobic environment. The staff were amazing!!! At all times my dignity was respected guiding me through the whole process in a calming, caring and professional manner. Thank you very much" (CareOpinion.org.uk)

6. Consider my dignity and modesty:

"I can feel disempowered when I have very little clothing on. I was laid on the bed obviously naked from the waist up, it felt really impersonal you know there was nobody having a chat with me at all, it was just all business and you just go with it because you want the best" (Support 4 All study)

"Help us cope, help us to feel that we have some control" (Support 4 All Research study)

7. Keep me informed during my appointment and at each stage of my journey, including the reason for any changes or delays to my results:

"I need to know that I have not been forgotten. I am likely to worry if I don't hear from you within the time frame I was told. If you have to re-arrange my appointment be honest with me and explain why, so that I feel valued"

"Please don't send a recall letter to me when there is nobody for me to talk to, I was extremely worried"

8. Make yourself aware of all my relevant medical and personal information required to deliver the best care for me:

"If you don't have some information that you feel you should have please take time to find it. Let me know what is happening and why. Don't risk making a wrong decision about my care to save time, please ask me. Take time to use the information available on the Patient Information System and to update this with relevant information about me as a person"

9. Be aware of my limitations but please do not make assumptions about me:

"Be gentle with me if I am struggling to walk, talk, lie down or straighten my arm/leg. Please explain to me why you want me to do any of these things and try to help me if I tell you I can't do something. Work with me to come up with alternatives that I can try. Be patient with me. Consider alternative tests or positions. Adapt your technique. Don't continue regardless as this may result in an unsatisfactory outcome"

10. Make sure my care is individualised to my needs, build in time for genuine discussion about the options that are available and allow for shared decision-making. I want to be involved, there should be no decision about me without me:

"I would like you to explain who has asked for me to have this test/treatment and why it is important for me specifically. I need time to ensure I agree with the plan for my care and it would help if you can check with me that nothing has changed since I last saw anyone for this episode of my care. Confirm that I know why I am here and allow me to choose anything I can related to my test, for example which arm you put the needle in if possible"

"I was given a CT scan because the wait for MRI was too long. The MRI was follow-up and no one spoke to me at any stage to explain why or ask me whether I would prefer to wait for the MRI rather than have a CT"

11. Take into consideration my family member and/or carer who may be with me. They may have my best interests at heart or conversely their actions may remove my control:

"Please ask who has come with me today and ask what their relationship with me is. Talk to us both and give my family member/carer the chance to ask questions. Explain to us both about how I will receive my results, this will help us to remember the information. Ensure that anyone with me can come and help me to undress and dress if required. Allow them to stay with me during any preliminary tests **if I want them to** (even if I'm an adult) and if it is safe for them to do so"

"Consider allowing me to record the consultation if my family member/carer is unable to stay with me"

12. Let me know what happens next, timescales and people to contact if needed:

"I need to feel assured that when I leave I am not forgotten and that I am well-informed about what will happen next"

13. Be honest and transparent about any findings:

"Do not hide behind your job. I don't want you to divulge anything that is not going to help me or that you are not qualified to but if you know the answer to a question don't be vague in your reply as it is likely to make me worry more. Tell me who will be able to give me the information I need and when"

"I'd got questions which were way off his understanding scale you know about what bra can I wear, and you know does it matter if it's underwired and that sort of thing, he'd just no idea...I did get some answers as time went on but when you are starting you want to know then" (SuPPORT 4 All study)

"I'd prefer to get a copy of the radiology report as well as getting a filtered version from my GP"

14. Be honest with me when things go wrong:

"Talk to me and my family and give us time to ask questions and have our concerns addressed. Don't try to hide what happened. Find time to talk to me about it"

15. Consider patient centred approaches to booking and appointment systems:

"I have a life outside of being a patient so let me decide which is the most important to me. Help me to achieve this balance"

"Be mindful of the impact a changed appointment might have on me"

"I went to the radiology dept. for an MRI on May 28th and was told the scanner was broken. I asked when it had broken down and was told the night before. No one had bothered to phone me until 12.00 noon the next day when I had just arrived in your parking lot for my appointment so I made an un-necessary journey. I could understand if it had only just happened" (CareOpinion.org.uk)

Service Delivery - Guidance for Members/Practitioners/Staff

		Core value	Guidance	Resources
	1	Introduce yourself and tell me your role in the management of my care	The SCoR Code of Professional Conduct ³ states that, "You must communicate effectively and appropriately with patients, introducing yourself and giving relevant information during their examination or treatment".	https://www.sor.org/learning/document-library/code-professional-conduct/section-1-relationships-patients-and-carers
			The SCoR strongly advocates the "Hello my name is" campaign.	https://www.sor.org/about-radiography/patient- information/hellomynameis-campaign
	2	Treat me as an individual and explain the purpose of the	Empower patients by making them feel individual – refer to this useful resource on patient-centred care from the Health Foundation.	http://personcentredcare.health.org.uk/
	to the management of my	Reflect on the effectiveness of your communication by using this useful set of six articles about person-centred communication.	https://www.nursingtimes.net/clinical-archive/assessment-skills/communication-skills-1-benefits-of-effective-communication-for-patients/7022148.article	
			Get involved in national initiatives such as 'What Matters to You'.	https://www.england.nhs.uk/what-matters-to-you/
	3	Find out what is important to me	There is a developing body of work looking at <u>values-based</u> <u>practice.</u>	 The Collaborating Centre for Values-based Practice in Health & Social Care (2016) http://valuesbasedpractice.org/ Strudwick R. & Newton-Hughes A. (2017). Values-Based Practice in Radiography. https://content.yudu.com/libraryHtml/A42w61/ImagingandTherapyPra/reader.html?page=10 Zdenkowski N, B Butow P., Tesson S., Boyle F. (2016). A systemic review of decision aids for patients making a decision about treatment for early breast cancer. https://content.yudu.com/libraryHtml/A42w61/ImagingandTherapyPra/reader.html?page=10 In Imagingand Therapy Practice of the Struck of the S

		Core value	Guidance	Resources
			Ensure your information is produced in an evidence-based way using national guidelines.	https://www.kingsfund.org.uk/blog/2016/11/producing-quality-patient-information https://www.pifonline.org.uk/
	4	Provide me with high quality patient information and check I am informed enough to consent to	Engage patients as partners in making sure information is accessible and appropriate to their diverse needs. There are great examples of collaborative working with patients to develop patient information videos. This resource has been developed by researchers at University College London.	https://www.ncbi.nlm.nih.gov/pubmed/29042474/
		proceed	Social Media can be used effectively to inform and advise patients about imaging and radiotherapy. Good practice guidelines in the use of Social Media can help with this.	http://www.hcpc-uk.org/registrants/socialmediaguidance/ https://www.sor.org/learning/document-library/somerad- guidance-radiography-workforce-professional-use-social-media
			The SCoR website has a link for patients.	https://www.sor.org/about-radiography/patient-information
		Ensure that I understand your role	Ensure that you are up-to-date with the latest SCoR Code of Professional Conduct ³ and HCPC Standards of Proficiency. ⁴	https://www.sor.org/learning/document-library/code-professional-conduct http://www.hcpc-uk.org/assets/documents/10000DBDStandards
	5	and make me feel confident and safe in your care	Consider sharing QA results with patients, for example, displaying equipment performance statistics or patient satisfaction surveys on relevant waiting room notice boards. You might also consider displaying information about key staff with an overview of their roles.	Local resources

	Core value	Guidance	Resources
		Ensure you are up-to-date with contemporary thinking about dignity.	Example: Gallagher A (2004) Dignity and Respect for Dignity - Two Key Health Professional Values: Implications for Nursing Practice Nursing Ethics 2004 11 (6) 587-599
6	Consider my dignity and modesty	The Dignity in Care campaign run by the National Dignity Council has some useful resources and a closed Facebook Group "Dignity in Action".	https://www.dignityincare.org.uk/About/Dignity_in_Care_campaign/ https://www.facebook.com/groups/289089744481097/
7	Keep me informed during my appointment and at each stage of my journey, including the reason for any changes or delays to my results	Good practice could be to indicate waiting times in the waiting room along with the name of the person in charge at that time.	Local resources
8	Make yourself aware of all my relevant medical and personal information required to deliver the best care for me	The SCoR Radiographic Informatics Group (RIG) can help with queries regarding the safe and effective management of patient data	https://www.sor.org/practice/hot-topics/radiographic-informatics

	Core value	Guidance	Resources
9	Be aware of my limitations but please do not make assumptions about me	Assess the individual needs of the patient within your care. Take time to learn about the issues related to specific groups of people and to ensure these are not exacerbated during Imaging and Radiotherapy. In the Five Year Forward view ¹ , patients are referred to as 'experts by experience'. Learn from these experiences by reading and valuing patients' stories. These can be found on patient support group websites such as Macmillan and also in more formal publications such as 'Somebody I Used to Know', a moving account of a patient developing dementia.	https://community.macmillan.org.uk/ Somebody I Used to Know, Wendy Mitchell, Bloomsbury published 01-02-2018 ISBN 9781408893340
		Specialist organisations, for example the Alzheimer's Society provide information for Health Professionals to support them in understanding the patients in their care.	https://www.alzheimers.org.uk/dementia-professionals
		DiSCOVER is a group of patients with osteoporosis who have written about their experiences within an imaging department.	https://www.radiographyonline.com/article/S1078-8174(18)30043- 9/abstract
10	Make sure my care is individualised to my needs, build in time for genuine discussion about the options that are available and allow	Make sure you are informed about the guiding principles of Shared Decision Making.	https://www.england.nhs.uk/shared-decision-making/
- 10	for shared decision-making. I want to be involved, there should be no decision about me without me	A wide set of resources can also be found on the Health Foundation's website.	https://www.health.org.uk/search?search=shared%20decision%20 making

	Core value	Guidance	Resources
		NHS safeguarding guidelines will help you understand your role in protecting patients whilst taking into account the role of the carer.	https://www.england.nhs.uk/ourwork/safeguarding/
	Take into consideration my family member and/or carer who may be with me. They may have my best interests at heart or conversely their actions may remove my	More specifically, NICE provide guidelines to help you support those living with dementia and their carers.	https://www.nice.org.uk/guidance/ng97
11		The Medical Protection Society explains the issues related to patients wanting to record their consultations.	https://www.medicalprotection.org/uk/practice-matters-issue- 7/digital-dilemmaspatients-recording-consultations
	control		https://www.cqc.org.uk/guidance-providers/gps/nigels-surgery-62-photography-making-using-visual-recordings-patients
		The SCoR has guidance on advocacy and consent	https://www.sor.org/learning/document-library/patient-advocacy https://www.sor.org/practice/obtaining-consent
12	Let me know what happens next, timescales and people to contact if needed	Read local policies on patient pathways and results ensuring your knowledge about local practices is up to date. Be confident in the information you give to patients about the next step in their care.	Local resources

ì	Core value	Guidance	Resources
		It is important you work within your scope of practice but that you also understand and according to your local protocols.	https://www.sor.org/learning/document-library/scope-practice-2013 https://www.sor.org/learning/document-library/diagnostic-radiography-survey-scope-radiographic-practice-2015 https://www.sor.org/learning/document-library/guidance-out-hours-working-and-your-personal-scope-practice https://www.sor.org/learning/document-library/scope-practice-assistant-practitioners
13	Be honest and transparent about any findings	However, do not be afraid to challenge the traditional boundaries if you have ideas which could improve patient experience and care. HCPC Standards of Proficiency ⁴ (9.3) require you to "understand the need to engage service users and carers in planning and evaluating their diagnostic imaging and interventional procedures or their radiotherapy pre-treatment planning, treatment and follow-up" and (9.4) "be aware of the need to empower service users to participate in the decision-making processes related to their radiotherapy or diagnostic imaging examination". These standards may require an element of disclosure not traditionally practiced within your department.	http://www.hcpc- uk.org/assets/documents/10000DBDStandards of Proficiency Rad iographers.pdf
	Be honest with me when things go	Access the joint response of the Society of Radiographers and the College of Radiographers to the Final Report of the Independent Inquiry into care provided by Mid Staffs NHS Foundation Trust.	https://www.sor.org/learning/document-library/joint-response-society-radiographers-and-college-radiographers-final-report-independent-inquiry-care
14	wrong	•	https://www.cqc.org.uk/guidance-providers/regulations- enforcement/regulation-20-duty-candour
		Ensure you are also aware of your own Employer regulations.	Local resources

	Core value	Guidance	Resources
15	Consider patient-centred approaches to booking and appointment systems	Have your appointment systems been established to ensure staff and resource efficiency or are they centred on patient preference? Take time to reflect on this. Work in partnership with patients to explore patient-friendly systems such as choose and book, walk-in systems and online booking options. The Always Events initiative has useful tools to help with this.	https://www.england.nhs.uk/always-events/

Section 2: Service Development for Person-Centred Care

Core values

"When you are designing and re-designing services I would like it if you could consider the following points"...

1. Include me in the team which discusses and develops diagnostic imaging and radiotherapy services and make sure changes are integrated with all other services on my pathway:

"I am the person experiencing the service so am the best person to advise you if it works and suggest any changes. New developments should have a benefit to me rather than be based on finances and resources"

"The worst part for me is always the wait for the results letter to drop through the letterbox - wouldn't it be wonderful to have a support-line' we could call up at this time to help us through that period of time"

(www.WoMMeN.org.uk research participant)

2. Invite me to be involved in giving relevant feedback but make sure this is valuable and acted upon:

"You need to know what is important to me and not just make assumptions. I have given up my time to complete feedback forms so would like to know what the outcome is. There should be no decision about me without me"

3. Bring in expertise from charities and peer-support groups to inform your ideas:

"They have a different kind of expertise which is often very specialised. Patients are experts by experience"

4. Acknowledge when errors have been made, consider my complaints and pass these on to the team so lessons can be learned:

"All I want to do is to make sure it doesn't happen again"

"My complaint and your response to it may have a positive impact on how the service develops"

5. Invite me to contribute to the quality of service staff:

"I have always found a patient interview panel to be beneficial and a positive experience. As patients we are able to connect with the interviewees as to what we would like (and need) from the staff working with us"

(CareOpinion.org.uk)

Service Development - Guidance for Members/Practitioners/Staff

	Core value	Guidance	Resources
1	Include me in the team which discusses and develops diagnostic imaging and radiotherapy services and make sure changes are integrated with all other services on my pathway	Engage patients in activities to evaluate the service and also to identify improvements. One such initiative is from the Institute of Healthcare Improvement: Always Events. Radiographers from the Warrington and Halton Hospitals, Cheshire, are piloting the scheme which has included simple but effective actions e.g. advising patients about waiting times.	https://www.england.nhs.uk/always-events/
2	Invite me to be involved in giving relevant feedback but make sure this is valuable and acted upon	Use the notice boards to display actions you have taken as a result of patient feedback. Involve patients in addressing feedback issues to develop the service.	Local resources
3	Bring in expertise from charities and peer-support groups to inform your ideas	Specialist patient communities can help you consider issues that are specific to a particular group of patients. One example is the Asian Breast Cancer group in Manchester. Using this specialist advice will make sure your practice is sensitive to a diverse set of needs.	https://asianbreastcancersg.org/
4	Acknowledge when errors have been made, consider my complaints and pass these on to the team so lessons can be learned	Access the joint response of the Society of Radiographers and the College of Radiographers to the Final Report of the Independent Inquiry into care provided by Mid Staffs NHS Foundation Trust.	https://www.sor.org/learning/document-library/joint-response-society-radiographers-and-college-radiographers-final-report-independent-inquiry-care
5	Invite me to contribute to the quality of service staff	Include patients and public on staff recruitment panels.	https://www.nhsemployers.org/your-workforce/recruit/employer-led-recruitment/children-and-young-people-in-the-recruitment-process

Section 3: Education towards Person-Centred Radiography

Core values

"When you are educating new radiographers or developing experienced staff, I would like it if you could....

1. Include real life, authentic patient experiences as part of learning:

"There is no substitute for the real thing. Make sure cases are authentic rather than contrived"

2. Invite me to talk to students and staff about my lived experiences:

"Many patients are willing to share their experiences to benefit both research and learning"

"Clinicians who become patients are often amazed at life on the other side of the counter. What is important to a patient may be low on the clinician's list of priorities"

3. Invite me to be involved in assessing students' patient care skills:

"Acronyms are part of every industry. The medical profession is no different and the patient experience can only be improved when patients have full command of what is being communicated"

"Language difficulties where patient or clinician does not have English as a first language can also present difficulties"

"I would like to comment on the student's holistic approach to my care"

4. Invite me to be involved in the development of courses of study:

"I might have some very innovative ideas about the things students should be taught based on my experience as a patient or carer that will add another perspective to their course"

5. Invite me to be involved in the selection of students:

"Once a student has shown the academic ability to apply for further advanced training / career development, why shouldn't I be involved to strengthen the quality of the panel? I'd be looking for different things as a patient"

6. Recruit students with compassion in mind, and educate and support them to embed compassion in their practice:

"As well as recruiting for compassion, it is about embedding compassion throughout the training, by ensuring the students are placed in teams where compassion towards patients, fellow staff and students is modelled to a high standard and it is seen as the norm"

"Education about compassion fatigue and how to ensure it is minimised is also crucial"

7. Encourage students and staff to consider exploring patient experiences in their research options:

"Extending knowledge in the field of radiography shouldn't just be focussed to technological developments"

"Filling in questionnaires often frustrates because the questions / options for comment often don't allow or reflect what the patients feel about the treatment / service they have been provided"

8. Develop and use materials which focus on person-centred care, making this a mandatory subject for CPD:

"It's very important that qualified staff are up-to-date in terms of their knowledge and skills but this should extend beyond critical topics like life support. Communication and patient-centred care are skills that are needed to support every single patient, every single day"

9. Educate staff (clinical and academic) and students about why and how to work with me as a partner to improve care:

"As an observer and volunteer, I am amazed that clinicians, maybe / understandably, appear to be totally focussed on being a clinician when often they are only seconds away from being a patient.

Patients have a wealth of different types of knowledge because they are 'experts by experience'"

"They should not be afraid to tap into this expertise and should be equipped with the skills to engage in new ways of communicating with patients"

10. Take time to educate school children and other members of the public about radiography, imaging and radiotherapy:

"They would develop an understanding of the profession and equipment, and of what may happen to them or a loved one if they need treatment. Removing fear using a non-threatening environment"

"Makes sure that they apply to become a radiographer having been fully informed"

Education - Guidance for Members/Practitioners/Staff

	Core value	Guidance	Resources
		Use experiences reported by patients online – for example on the Care Opinion website.	https://www.careopinion.org.uk/
1	Include real life, authentic patient experiences as part of learning	Include practitioners who are/have been patients. Their understanding of the clinical encounter from multiple perspectives can offer a unique perspective.	https://www.youtube.com/watch?v=Z5yOiFOVUmc
2	Invite me to talk to students and staff about my lived experiences	An example of good practice: In collaboration with a service user, the University of Exeter has developed a series of workshops to increase student radiographers' understanding of depression in service users. These workshops also aim to develop a greater understanding of the potential impact depression can have on patient-radiographer interactions. The students work through exercises to share their understandings of depression using visual mediums created in their small groups. They then discuss these with the wider group and listen to the experiences of the service user. The session is summed up using video clips of stories from service users who suffer with depression. These videos are open access.	http://www.exeter.ac.uk/mooddisorders/leg/ourstories/
3	Invite me to be involved in assessing students' patient care skills	Include patients as assessors in simulated clinical assessments in the university setting. Ask a patient for feedback on the student's communication skills following an authentic clinical assessment on placement.	https://www.radiographyonline.com/article/S1078-8174(15)00007-3/abstract

	Core value	Guidance	Resources
4	Invite me to be involved in the development of courses of study	HCPC Standards of Education and Training ⁵ (SET 3.7) requires that "service users and carers must be involved in the programme". Patients can be involved in all stages of student learning and assessment, this even includes being a member of the programme development team.	https://www.health.org.uk/sites/health/files/CanPatientsBeTeachers.pdf
5	Invite me to be involved in the selection of students	Invite patients to be part of student selection processes. This might include developing shortlist criteria, being a member on interview panels or observing and scoring students during group interview exercises.	https://www.bmh.manchester.ac.uk/connect/social-responsibility/communities/case-study-engagement-recruitment/
6	Recruit students with compassion in mind, and educate and support them	Ensure your recruit using a Values-Based model.	https://www.hee.nhs.uk/sites/default/files/documents/VBR Frame work%20March%202016.pdf
6	to embed compassion in their practice	Educate about compassion fatigue and burnout and how to ensure these are minimised.	http://www.compassionfatigue.org/index.html
7	Encourage students and staff to consider exploring patient experiences in their research options	Talk to members of the public via voluntary and/or community support groups about what research should be undertaken to explore the patient experience.	https://www.gov.uk/find-a-community-support-group-or- organisation
8	Develop and use materials which focus on person-centred care, making this a mandatory subject for CPD	Access e-learning for health (eLFH) person-centred radiography tools. Although eLFH does not have radiography specific tools, their care certificate modules are excellent.	https://www.skillsforcare.org.uk/Learning-development/Care- Certificate/Care-Certificate.aspx

	Core value	Guidance	Resources
9	Educate staff (clinical and academic) and students about why and how to work with me as a partner to	Share these guiding principles in staff meetings and use them to stimulate discussions at CPD events. New ways of working with patients and the public requires us to reconsider our role and position as professionals.	https://www.idunn.no/nordisk_valfardsforskning/2018/01/service_user_involvement_and_repositioning_of_healthcare_pr
	improve care	Provide enhanced communication skills training which will enable radiographers to engage in frank and transparent discussions with patients about their clinical case.	https://www.england.nhs.uk/shared-decision-making/how-to-make-shared-decision-making-happen/how-we-can-make-shared-decision-making-happen-preparing-professionals/
		Engage radiography students as ambassadors to visit schools and colleges – they will have recent links with these places and will be proud to show their teachers and peers about radiography.	https://salfordradiography.wordpress.com/2018/01/08/the-shows-on-the-road/
10	Take time to educate school children and other members of the public about radiography, imaging and radiotherapy	Promote the profession by going to places where the public are, for example, online and on social media. This is particularly useful for radiographers engaged in Public Health.	https://www.facebook.com/NorthMidlandsBreastScreeningService/
		Engage in World Radiography day.	https://www.sor.org/about-radiography/world-radiography-day
		Use these channels to elicit information from the public about what their experiences of the profession are too. Partnership working requires a two-way conversation.	

Section 4: Person-Centred Radiography Research

Core values

"When you are undertaking research related to radiography I would like it if you could"...

1. Understand the value patients and the public can bring to research and work in partnership with us rather than just using us as research participants:

"I can provide insight into existing care from the patient perspective, I can highlight what matters most to patients and the public about your current service, about where your service or care is lacking or could be improved and I can provide different ideas about what interventions and care will be best tolerated"

"I can also give you feedback on your research method, making sure you explain clearly what your study is about; communicate more sensitively with people; design studies so they are easier to take part in; and share your results with people I know"

"We are the DiSCOVER group; a group of patients who have osteoporosis and have been working together for 6 months assisting researchers. We were involved in a number of workshops between January and June 2017 setting our priorities for osteoporosis research and one of the key themes we identified was to raise the profile of osteoporosis"

2. Ensure research involving patients and the public is informed by national guidelines and good practice:

"It is important to ensure my input is managed correctly and with care. It is also important that my time and contribution is adequately reimbursed, so please make sure your research funding bid incorporates adequate costs to pay for my time and travel costs"

"As a patient working as part of the research team I need some training and support. In particular I need:

- Help with jargon
- Help in understanding what is meant by research
- Training in how to carry out research
- To know how the research will be funded and how I will be able to claim expenses volunteers should not be expected to be out of pocket childcare, travel should always be factored in. How it will affect my benefits
- To know what will happen if I become unwell a concern for patients with long-term illnesses
- A system of mentoring
- To receive feedback on my input"

3. Consider the diversity of patients - make sure people who are like me are involved in your research:

"I need to know that your research findings really do represent my own views and experiences. This will only happen if you try to engage with patients from relevant groups"

4. Share your research with me in a language I understand, at regular intervals throughout the project as well as at the end:

"As a patient I am a key stakeholder of research and need to be able to read and interpret the results so that I can use it to make informed choices about my care"

"If I have given my time to input into your research I deserve to be informed about the outcomes"

5. Make sure all your radiography research includes my voice at each stage of the research process from design to dissemination:

"I'd really like to get involved in more clinical research but I don't always get to know about such opportunities"

"I'd like to be involved as a participant but also as a member of the research team"

6. Make sure any images you take of me as part of the research study follow guidelines about incidental findings:

"I don't know if you will tell me if you find something unexpected and this worries me, surely you've an obligation to do that – right?"

 $Research - Guidance \ for \ Members/Practitioners/Staff$

		Core value	Guidance	Resources
	1	Understand the value patients and the public can bring to research and work in partnership with us rather than just using us as research participants	Healthtalk.org is a partnership between the charity DIPEx and the Health Experience Research Group (HERG) at the Nuffield Department of Primary Healthcare Science, University of Oxford. This site includes a section which provides the patient perspective on being involved in research, including topics such as 'what is patient and public involvement ('PPI') in research?' and 'why does it matter?'	http://www.healthtalk.org/peoples-experiences/improving-health-care/patient-and-public-involvement-research/what-patient-and-public-involvement-and-why-it-important
			It is also important to give patients and public feedback on what their contribution to the research has been.	https://www.ncbi.nlm.nih.gov/pubmed/29654644
	2	Ensure research involving patients and the public is informed by national guidelines on good practice	INVOLVE is part of, and funded by, the National Institute for Health Research and supports active public involvement in NHS, public health and social care research. It contains a wide range of guidance documents and tools.	http://www.invo.org.uk/
	3	Consider the diversity of patients - make sure people who are like me are involved in your research	Explore currently available advocacy groups so that a wide range of representative people can be involved. Register your project with national groups such as the NHS National Institute for Health Research or INVOLVE's Community groups	https://www.peopleinresearch.org/ http://www.invo.org.uk/communities/invodirect/
			Regional research groups also exist such as the North West People in Research group	https://www.northwestpeopleinresearchforum.org/
	4	Share your research with me in a language I understand, at regular intervals throughout the project as well as at the end	Ask patients to read lay versions of summaries or research results intended for public dissemination, they will be able to show you where your language makes the results difficult to understand, improving the readability of your outputs for lay consumption. Use the publication by National Voices to make your information and results easier to understand.	https://www.nationalvoices.org.uk/sites/default/files/public/publications/improving information.pdf

	Core value	Guidance	Resources
5	Make sure all your radiography research includes my voice at each stage of the research process from design to dissemination	Think about the design of your recruitment strategy so that eligible patients for your research get the opportunity to participate, i.e. they aren't missed. As well as registering your research on the sites listed for core value 3, consult patients and patient groups to ensure your recruitment strategy will allow you to reach as many eligible patients as possible. Consider using social media to increase access to a wide range of patients and public. INVOLVE guidelines on the use of Social Media are a useful resource.	http://www.invo.org.uk/posttypepublication/guidance-on-the-use-of-social-media/
6	Make sure any images you take of me as part of the research study follow guidelines about incidental findings	Make sure you include full details of how incidental findings are handled in your consent form. The RCR has guidelines on the Management of Incidental Findings during Research Imaging (2011).	https://www.rcr.ac.uk/sites/default/files/docs/radiology/pdf/BFCR% 2811%298 Ethics.pdf

Key Resources

For ease of reference, links have been provided throughout the document however the following resources are considered key reference material so are cited in full again here.

- **1.** NHS (2014), Five Year Forward View [available at] https://www.england.nhs.uk/wpcontent/uploads/2014/10/5yfv-web.pdf
- 2. SCoR and CoR (2018), The 2018-20 Strategy of the Society and College of Radiographers [available at] https://www.sor.org/system/files/article/201807/strategy_planning_a4_leaflet_2018.pdf
- **3.** SCoR (2013), SCoR Code of Professional Conduct [available at] https://www.sor.org/learning/document-library/code-professional-conduct
- **4.** HCPC (2013), Standards of Proficiency –Radiographers [available at] http://www.hcpc-uk.org/assets/documents/10000DBDStandards of Proficiency Radiographers.pdf
- **5.** HCPC (2017), Standards of Education and Training [available at] http://www.hcpc-uk.org/assets/documents/10000BCF46345Educ-Train-SOPA5 v2.pdf

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