

Shared Decision Making and Consent: Phase 1 Final Report

Appendix E

Webinar Materials and Participants

June 2021

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1 High Level View of the Standard

A high level view of the standard was introduced to participants using Microsoft Powerpoint®:

Overview of the draft information standard



The issue	Consultation details	Supporting the shared decision	Documenting consent
<ul style="list-style-type: none"> • Diagnosis, problem or issue related to the shared decision made. 	<ul style="list-style-type: none"> • Where it was • When it was • Who was there • By video or telephone • Use of interpreter • Video or audio recorded 	<ul style="list-style-type: none"> • Before the appointment • During the appointment • After the appointment • Decision support tools • Measuring effectiveness 	<ul style="list-style-type: none"> • Record of which standard NHS consent form (1 – 4) was used • Where to find it • Not a fully digitised consent form

Overview of the draft information standard



Name	Description
Supporting the shared decision	A record of the interventions that have supported a shared decision. This includes actions taken before, during and after (or in-between) appointments where a shared decision was discussed. <i>NICE: "Offer people interventions that support shared decision making at different stages, including before, during and after discussions with a healthcare professional, so that they are fully involved throughout their care."</i>
→ Preparation	A record of the actions taken to prepare the patient to make a shared decision before the appointment. This should include a summary of any resources the person was offered to prepare them for the decision making process. <i>NICE: "Before an appointment where a decision will be discussed, offer the person access to resources in their preferred format..."</i>
→ Discussion record	A record of the actions taken to support shared decision making during the appointment.
→ Post-appointment actions	A record of the actions taken to support the shared decision after the appointment. For example, printouts summarising the options or decisions made, signposting to relevant online or physical information resources. <i>NICE: "Give people resources to help them understand what was discussed and decided in their appointment."</i>
→ Performance measures	A record of any performance measures used for measuring the effectiveness of shared decision making. E.g., CollaboRATE, Observer OPTION 5, Observer OPTION 12, SDM-Q-9 / SDM-Q-Doc etc.

Drilling down into the Discussion record

Name	Description
Discussion record	A record of the actions taken to support shared decision making during the appointment.
→ Shared decision cluster	A generic shared decision cluster.
↓ Agenda setting	A record of the agenda setting process undertaken to support the shared decision.
<i>NICE: "Agree an 'agenda' at the start of each appointment to prioritise together what to discuss."</i>	
↓ Decision dialogue	A record of the dialogue preceding the decision including the information shared that a person wanted or needed to know in order to make a decision.
<i>GMC: "You must give patients the information they want or need to make a decision. This will usually include... diagnosis and prognosis, uncertainties about the diagnosis or prognosis, including options for further investigation, options for treating or managing the condition, including the option to take no action, the nature of each option, what would be involved, and the desired outcome, the potential benefits, risks of harm, uncertainties about and likelihood of success for each option, including the option to take no action."</i>	
↓ Decision support tools	Record of any decision support tools used.
<i>NICE: "Use patient decision aids as one part of an overall 'toolkit' to support shared decision making..."</i>	
↓ Specific SDM models	Including Ask 3 questions, BRAN (Benefits, Risks, Alternatives, Nothing), and Three talk model.
<i>NICE: "The three-talk model is a practical model of how to do shared decision making that is based on following choice, option, and decision talk stages during the consultation."</i>	

Drilling down into Decision dialogue

Name	Description
Decision dialogue	A record of the dialogue preceding the decision including the information shared that a person wanted or needed to know in order to make a decision.
→ Establishing the conversation	A description of what was said to: Establish collaboration & consultation purpose, clarify expectations, declare alternatives (including doing nothing) and explore patient understanding and goals & hopes.
<i>NICE: "The studies looking at what was effective in shared decision making showed the strongest support for eliciting people's expectations, values, priorities, and goals..."</i>	
→ Options	Record of the options discussed.
→ Risks	Record of the risks discussed for each option.
<i>GMC: "Recognised risks of harm that...anyone in the patient's position would want to know... [or that] the patient would consider significant for any reason...any risk of serious harm, however unlikely it is to occur...expected harms..."</i>	
→ Benefits	Record of the benefits discussed for each option.
<i>GMC: "You must give patients clear, accurate and up-to-date information, based on the best available evidence, about the potential benefits and risks of harm of each option, including the option to take no action."</i>	
→ Decision	Record of the decision and opportunity for review.
<i>NICE: "Make a joint decision or plan about treatment or care and agree when this will be reviewed."</i>	

2 Use Case Scenarios

The use case scenarios presented in the webinar breakout sessions can be found in appendix C of the Phase 1 Report (separate document).

3 Session Groups and Participants

Due to technical issues during the webinar a minority of participants were not allocated to the breakout session as intended/indicated below. Participants were invited to give comment on shared decision making and the draft standard based on their professional and lay experience, irrespective of the use case scenario presented.

3.1 Main Session (only)

Participant Name	Organisation	Title / Role
	PRSB	Communications Officer
	NHS England & NHS Improvement PPV Board	Service user
	N/A	Service user
	Patient Information Forum	Projects and Partnerships Manager
	Royal College of Physicians	Cardiac Electrophysiologist, Clinical Director Digital Health
	PRSB	Retired Geriatrician
	Defence Medical Services	Deputy Head - Medical Policy and Intensive Care Medic
	Ear, Nose and Throat UK (ENT UK)	Consultant ENT/ Head & Neck and Thyroid surgeon
	University Hospitals Plymouth NHS Trust	Vascular Surgeon
	Betsi Cadwaladr University Health Board	Consultant in Renal Medicine
	British Association of Anaesthetic Plastic Surgeons	President and Consultant Plastic and Hand Surgeon
	National Digital Services (NDS)	Associate Director, Clinical and Health Service Design
	NHSEI	Occupational Therapist
	Chartered Society of Physiotherapy	Health Informatics Lead
	Chartered Society of Physiotherapy	Professional Advisor
	Versus Arthritis	Senior Clinical Policy Advisor
	techUK	Programme Manager
	CASPA	Cofounder - Person Centred Software

	ConsentWise	Consultant Orthopaedic Surgeon
	EIDO Healthcare	Director
	Wellbeing Software	Product Director
	Copeland Clinical Ai (C2-Ai)	CEO
	Cerner	Senior Regulatory Strategist, National Standards Practice
	Safety and Learning Lead (London)	Justine Sharpe
	Capsticks medical malpractice insurance team	Partner
	Scottish Government	Policy Lead for Self Management and Health Literacy
	Public Health England	CCIO
	Delivering Workplace Strategies and Workforce Development	Independent Librarian
	NHS Wales	Clinical Law and Ethics Legal Advisor

3.2 Main Session & Elective Surgery Breakout

Participant Name	Organisation	Title / Role
	Mid and South Essex NHS Foundation Trust	Clinical Lead - Consultant Vascular Surgeon & CCIO
	N/A	Parent carer and citizen rep
	RCS Patient and Lay Group	Service user
	Sherwood Forest Hospitals NHS Foundation Trust	Clinical Director for Patient Safety, Consultant Anaesthetist
	British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS)	President and Consultant Plastic and Reconstructive Surgeon

	Society of British Neurological Surgeons	Interim Chief Medical Officer/Consultant Neurosurgeon
	Society for Cardiothoracic Surgery in Great Britain & Ireland	Consultant Cardiac Surgeon & Clinical Lead for Cardiac Surgery
	British Association of Oral and Maxillofacial Surgeons	Consultant in Oral and Maxillofacial Surgery and past President
	North Bristol NHS Trust	Consultant Geriatrician
	Portsmouth Hospitals University NHS Trust	Consultant Anaesthetist
	North Bristol NHS Trust	Consultant Neurosurgeon
	Essex region	Locum GP
	Aneurin Bevan University Health Board	Consultant Musculoskeletal Physiotherapist
	Versus Arthritis	Commissioned Services Manager
	Resolve Digital/ ConsentWise	Clinical and Services Director and Consultant Trauma and Orthopaedic Surgeon
	ConsentWise	Orthopaedic surgeon
	NHSx	Product manager
	NHSx	Service designer
	NHSx	Delivery manager
	NHSx	Service designer
	Linklaters LLP	Professional Support Lawyer

3.3 Main Session & Polypharmacy Breakout

Participant Name	Organisation	Title / Role
	PRSB	Project Manager

	Royal College of Anaesthetists/ Guy's and St Thomas' NHS Foundation Trust	Clinical Lead – Consultant Anaesthetist
	N/A	Service user
	British Society for Rheumatology	Clinical Rheumatologist
	Brighton and Sussex Medical School	Senior Lecturer in Geriatrics and Stroke Medicine
	Sutton Coldfield Group Practice and NHD E/I	GP, RCGP Fellow for evidence and values and Personalised care team
	Royal Pharmaceutical Society	Policy Lead (Wales) and locum Pharmacist
	Royal Pharmaceutical Society	Consultant Pharmacist

3.4 Main Session & Gynaecology Breakout

Participant Name	Organisation	Title / Role
	NHS England	Personalised Care Manager – Shared Decision Making
	N/A	Service user
	Fair Treatment for the Women of Wales - patient-led women's health equality organisation	CEO
	Royal College of Anaesthetists	Obstetric anaesthetist, represents RCoA on the RCOG patient safety forum
	Royal College of Obstetricians & Gynaecologists	CCIO
	British Association of Day Surgery	President Elect & Head of Publications;

		Consultant Breast Surgeon
	British Society of Urogynecology	Chair, RCOG fellow and Consultant Urogynaecologist
	Royal College of Nursing	Fellow and member of the Women's Health Forum
	NHS Tower Hamlets CCG	GP, Principal clinical lead for integration and PCN Clinical Director
	General Medical Council	Standards and Policy, ethics advisor
	General Medical Council	Policy Officer

3.5 Main Session & Children Breakout

Participant Name	Organisation	Title / Role
	Centre for Perioperative Care (CPOC)	Project Citizen Lead
	N/A	Service user
	Academy of Medical Royal Colleges and NHS E/I	National Medical Director's Clinical Fellow
	Hull University Hospitals NHS Trust	Consultant Anaesthetist
	Sheffield Children's NHS Foundation Trust	Paediatrician
	St Marks National Bowel Hospital	Consultant Gastroenterologist
	Betsi Cadwaladr University, Health Board University of Chester	Senior staff (children's) nurse – CAMHS
	Allied Health Professionals Scotland	AHP Advisor, NHS National Services Scotland
	British Orthodontics Society	STR, Cumbria Hospitals
	Wellbeing Software	Product Manager

3.6 Main Session & Cancer Breakout

Participant Name	Organisation	Title / Role
	PRSB	CEO
	N/A	Service user
	Royal College of Radiologists	Patient Safety Adviser and Interventionalist Radiologist
	Royal College of Radiologists	Consultant Clinical Oncologist - colorectal cancer and lung
	Royal College of General Practitioners	GP and Cancer Clinical Adviser
	Hywel Dda University Health Board	Macmillan Clinical Lead Physiotherapist
	Macmillan	Nurse and Specialist Advisor for Treatment and Recovery
	Resolve Digital/ ConsentWise	Managing Director
	NHS England	Personalisation and Control Specialist

3.7 Main Session & Mental Health Breakout

Participant Name	Organisation	Title / Role
	PRSB	Director of strategy, comms and engagement
	N/A	Service user
	King's College London	Service user and SDM academic
	Black Country Health Care NHS Foundation Trust	Associate Medical Director, Consultant General Adult Psychiatrist

	University of Chester	Registered mental health nurse and lecturer
	Royal College of Nursing	Professional Lead for Nursing Support Workers and Long Term Conditions
	SWL STG	CNIO and Street Triage Nurse
	Royal College of General Practitioners	Clinical Representative for Dementia
	Age UK Cymru	Advocacy and Information Officer
	Bevan Commission	Bevan Commission Exemplar - Deaf Mental Healthcare and service provision
	North Yorkshire County Council	MCA DoLS Team Team Manager

3.8 Main Session & Long Term Conditions Breakout

Participant Name	Organisation	Title / Role
	PRSB	PRSB, Clinical director for health and care & Clinical Lead – GP
	National Voices	Health Policy Analyst and Researcher
	Royal College of Speech and Language Therapists	Head of Learning
	Academy of Medical Royal Colleges	Lay adviser and service user
	Compassion in Dying	Information Strategy and Development Manager
	Year of Care Partnership	Clinical lead, Endocrinologist and Diabetes Specialist Physician

	Academy of Medical Royal Colleges	RCoA deputy CEO
	Royal College of Surgeons of England	Consultant Orthopaedic Surgeon and Rcseng Council member
	Resuscitation Council	Policy officer
	Association Of Surgeons Of Great Britain & Ireland	Consultant in Emergency General Surgery and Major Trauma and Regional representative for Greater London
	St Marks National Bowel Hospital	Gastroenterology research fellow and Specialist Trainee Gastroenterologist
	Royal College of Nursing	Professional Lead for Mental Health
	Royal College of Nursing	RN Diabetes Nurse Consultant and Regional Genetic Diabetes Nurse
	NHS Tower Hamlets CCG	Practise Nurse
	Year of Care Partnership	National Director and Consultant Dietician
	Arthritis Action	Communications Manager
	Health and Social Care Alliance Scotland	Digital Health and Care National Lead
	NHS Wales Informatics Service/ Digital Health and Care Wales	National Clinical Informatics Lead – Public (Wales)
	PRSB	Membership Manager

3.9 Main Session & Genetic Conditions Breakout

Participant Name	Organisation	Title / Role
	PRSB	Project Analyst

	N/A	Carer
	Royal College of Physicians	Professor/Consultant in Clinical Genetics
	St George's, University of London	Reader Primary Care and Genomics
	NHS England and Improvement	Pharmacy Advisor - Genomics Unit
	Genetic Alliance	Director of Policy
	EIDO Healthcare	CEO
	Orcha	CIO
	Faculty of Public Health	Ethicist