

‘Nobody knows *me* better than *me*’

**The development and pilot-testing of a patient-targeted
complex intervention to prepare patients to participate
in shared decision-making**



Natalie Joseph-Williams

Additional Appendices

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Additional Appendix 2.1 – Search strategies for nine electronic databases

Applied Social Sciences Index and Abstracts (ASSIA) 1987>	
<p>((patient activation) OR (preference sensitive) OR (value* clarification) OR (informed decision) OR (patient choice) OR SU.EXACT.EXPLODE('Informed choice') OR 'patient preference' OR 'patient involvement' OR (SU.EXACT('Doctor-Patient communication') OR SU.EXACT.EXPLODE('Health professional-Patient communication'))) OR SU.EXACT.EXPLODE('Patient centredness') OR all(shared decision making) OR (SU.EXACT('Patient participation') OR SU.EXACT('Client participation') OR SU.EXACT('Perceived participation') OR SU.EXACT('Joint participation')) OR (decis* PRE/1 choic*) OR all(patient NEAR/3 decision making) OR SU.EXACT('Collaborative decision making') OR SU.EXACT('Decision making')) AND ((all(barrier*) OR facilitator* OR all(motivator*) OR (patient* AND (attitude* OR belief* OR expectation*)) OR all(acceptance OR willingness)) AND (SU.EXACT.EXPLODE('Competent patients' OR 'Dangerous patients' OR 'Long stay patients' OR 'Nonurgent patients' OR 'Outpatients' OR 'Patients' OR 'Private patients' OR 'Sectioned patients' OR 'Standardized patients' OR 'Uninsured patients') OR SU.EXACT('Clients') OR (patient reported) OR (patient identified) OR (patient NEAR/2 related)))</p>	

Cumulative Index to Nursing and Allied Health (CINAHL) 1982>	
S31	S17 and S30
S30	S24 and S29
S29	S26 or S27 or S28
S28	patient related
S27	'patient identified'
S26	patient reported
S25	(MH 'Patients')
S24	S18 or S19 or S20 or S21 or S22 or S23
S23	acceptance OR willingness
S22	motivator*
S21	patient* AND (attitude* OR belief* or expectation*)
S20	(MH 'Attitude of Health Personnel') OR (MH 'Attitude to Health') OR (MH 'Patient Attitudes')
S19	'facilitator*'
S18	'barrier*'
S17	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16

S16	'patient activation'
S15	'informed decision*'
S14	(MH 'Decision Support Techniques')
S13	'patient choice'
S12	'value* clarification'
S11	(MH 'Values Clarification')
S10	'patient preference'
S9	'patient involvement'
S8	'client participation'
S7	'Patient participation'
S6	'shared decision making'
S5	(MH 'Refusal to Participate')
S4	(MH 'Consumer Participation')
S3	'decis* AND choic*'
S2	'patient decision making'
S1	(MH 'Decision Making, Patient+') OR (MH 'Decision Making, Family') OR (MH 'Decision Making, Clinical')

British Nursing Index (BNI) 1985>

((barrier* NOT barrier* NEAR/2 method* NOT skin) OR all(facilitator*) OR SU.EXACT.EXPLODE('1:Patients ') OR all(patient* AND (attitude* OR belief* OR expectation*)) OR all(acceptance OR willingness)) AND (patient reported OR patient identified OR patient NEAR/2 related)) AND (all(decision making) OR all(patient NEAR/3 decision making) OR (shared decision making) OR SU.EXACT.EXPLODE('1:Patients ') OR (patient centredness) OR (SU.EXACT.EXPLODE('Nurse Patient Relations') OR SU.EXACT.EXPLODE('Midwife Patient Relations'))) OR all(patient participation OR client participation OR perceived participation OR joint participation OR patient involvement) OR (informed decision OR informed choice OR patient choice) OR all(patient preference OR value* clarification OR preference sensitive) OR (patient activation))

EMBASE 1947>

1	exp decision making/
2	(patient adj3 decision making).mp.
3	patient decision making/

4	(decis* adj choic*).mp.
5	exp patient participation/
6	refusal to participate/
7	shared decision making.mp.
8	patient involvement.mp.
9	patient participation.mp.
10	patient preference.mp. or patient preference/
11	value* clarification.mp.
12	patient choice.mp.
13	informed decision*.mp.
14	preference sensitive.mp.
15	patient activation.mp.
16	or/1-15
17	barrier*.mp.
18	facilitator*.mp.
19	attitude/
20	patient attitude/
21	(patient* and (attitude* or belief* or expectation*)).mp.
22	motivator*.mp.
23	(acceptance or willingness).mp.
24	or/17-23
25	exp hospital patient/
26	exp outpatient/
27	patient reported.mp.
28	patient identified.mp.
29	patient related.mp.
30	or/25-29
31	24 and 30
32	16 and 31
33	limit 32 to human

34	limit 33 to english language
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Medline 1946> and Medline in Process	
1	Decision Making/
2	(patient adj3 decision making).mp.
3	(decis* adj choic*).mp.
4	Patient Participation/
5	Refusal to Participate/
6	shared decision making.mp.
7	Choice Behavior/
8	Patient Preference/
9	patient involvement.mp.
10	exp Consumer Participation/
11	value* clarification.mp.
12	patient choice.mp.
13	informed decision*.mp.
14	preference sensitive.mp.
15	patient activation.mp.
16	or/1-15
17	barrier*.mp.
18	facilitator*.mp.
19	Attitude/
20	(patient* and (attitude* or belief* or expectation*)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
21	motivator*.mp.
22	(acceptance or willingness).mp.
23	Patient Acceptance of Health Care/
24	or/17-23
25	Patients/

26	inpatients/
27	Outpatients/
28	patient reported.mp.
29	patient identified.mp.
30	patient related.mp.
31	25 or 26 or 27 or 28 or 29 or 30
32	24 and 31
33	16 and 32
34	limit 33 to humans

PsycINFO Ovid 1806>	
1	decision making/
2	choice behavior/
3	(patient adj3 decision making).mp.
4	(decis* adj choic*).mp.
5	exp client participation/ or participation/
6	shared decision making.mp.
7	preferences/
8	patient preference*.mp.
9	patient involvement.mp.
10	values/
11	value* clarification.mp.
12	patient choice.mp.
13	informed decision*.mp.
14	preference sensitive.mp.
15	patient activation.mp.
16	or/1-15
17	barrier*.mp.
18	facilitator*.mp.

19	exp client attitudes/
20	(patient* and (attitude* or belief* or expectation*)).mp.
21	motivator*.mp.
22	(acceptance or willingness).mp.
23	or/17-22
24	exp patients/
25	patient reported.mp.
26	patient identified.mp.
27	patient related.mp.
28	or/24-27
29	23 and 28
30	16 and 29
31	limit 30 to english language

Scopus 1966>

((TITLE-ABS-KEY-AUTH('patient reported')) OR (TITLE-ABS-KEY-AUTH('patient related')) OR (TITLE-ABS-KEY-AUTH('patient identified'))) AND ((TITLE-ABS-KEY-AUTH(barrier* not method OR skin)) OR (TITLE-ABS-KEY-AUTH(facilitator*)) OR (TITLE-ABS-KEY-AUTH(motivator*)) OR (ABS(patient* AND (attitude* OR belief* OR expectation*)))) AND ((TITLE-ABS-KEY-AUTH(patient W/3 'decision making')) OR (TITLE-ABS-KEY-AUTH(decis* W/1 choic*)) OR (TITLE-ABS-KEY-AUTH('shared decision making')) OR (TITLE-ABS-KEY-AUTH(patient* W/3 choic* OR option*)) OR (TITLE-ABS-KEY-AUTH('patient involvement' OR 'patient cent??dness')) OR (TITLE-ABS-KEY-AUTH('value* clarification' OR 'patient preference' OR 'informed decision*')) OR (TITLE-ABS-KEY-AUTH('patient activation'))))

Web of Science 1981>

# 26	#24 AND #13 Refined by: Languages=(ENGLISH) Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On
# 25	#24 AND #13 Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On

# 24	#23 AND #19 <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 23	#22 OR #21 OR #20 <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 22	TS=(patient NEAR/3 identified) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 21	TS=(patient NEAR/3 related) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 20	TS=('patient reported') <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 19	#18 OR #17 OR #16 OR #15 OR #14 <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 18	TS=(patient* (acceptance OR willingness)) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 17	TS=(patient* AND (attitude* OR belief* OR expectation*)) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 16	TS=(motivator*) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 15	TS=(facilitator*) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 14	TS=(barrier*) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 13	#12 OR #11 OR #10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1 <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 12	TS=('patient activation') <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 11	TS=('preference sensitive') <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 10	TS=(value* clarification) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>

# 9	TS=(patient cent??dness) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 8	TS=(informed decision*) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 7	TS=(‘patient involvement’) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 6	TS=(patient* NEAR choic* OR option*) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 5	TS=(‘patient preference’) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 4	TS=(‘patient participation’) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 3	TS=(shared decision making) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 2	TS=(decis* NEAR/1 choic*) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>
# 1	TS=(patient NEAR/3 ‘decision making’) <i>Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=All Years Lemmatization=On</i>

Additional Appendix 3.1 – Inclusion/exclusion criteria of previous reviews

Duncan et al (2010) Shared decision making interventions for people with mental health conditions	
<i>Types of study</i>	Inclusion <ul style="list-style-type: none"> • Randomised controlled trials • Quasi-randomised controlled trials • Controlled before-and-after studies • Interrupted time series
<i>Types of participants</i>	Inclusion <ul style="list-style-type: none"> • Persons diagnosed with a mental health condition by any defined criteria (e.g. ICD-10 or DSM) • All ages • Public and private healthcare consumers • Professionals, service users, family and/or carers. Exclusion <ul style="list-style-type: none"> • Studies that included people with substance misuse problems where comorbid mental health conditions had not been assessed using DSM or ICD-10 criteria.
<i>Types of interventions</i>	Inclusion <ul style="list-style-type: none"> • Single/combination interventions • Compared to usual care or another intervention • Description sufficient enough for review authors to determine if it aimed to increase the degree of SDM between patient and provider • Targeted at providers, consumers, or carers/family members • Any mode/intensity of deliver Exclusion <ul style="list-style-type: none"> • Primarily a secondary interventions (e.g. anxiety management) • Consisted solely of information about condition • Aimed at enhancing communication between patient and provider, without focus on specific choice • Targeted at future care e.g. advanced directives
Kinnersley et al (2009) Interventions before consultations for helping patients address their information needs	
<i>Types of study</i>	Inclusion <ul style="list-style-type: none"> • Randomised controlled trials Exclusion <ul style="list-style-type: none"> • Controlled clinical trials • Prospective cohort studies • Studies without comparison groups • Individual case reports
<i>Types of participants</i>	Inclusion <ul style="list-style-type: none"> • Patients and/or their representatives (or carers) of all ages before ‘one-to-one’ consultations with doctors or nurses in healthcare settings Exclusion <ul style="list-style-type: none"> • Individuals or groups attending activities such as health promotion clinics or in-patients for whom there were not specific subsequent identifiable consultations • Individuals consulting other healthcare professionals
<i>Types of interventions</i>	Inclusion <ul style="list-style-type: none"> • Directed at individual patients, representatives or carers before a consultation and intended to help them address their information needs before the consultation Exclusion <ul style="list-style-type: none"> • Provided to patients during their consultations, for example information leaflets about illnesses or diseases, and decision aids • Symptom diaries, unless the material appeared to encourage identification of patient information needs as well as provision of information

	<ul style="list-style-type: none"> • Describe treatment options and effects of treatments • Intended to provide patients with more information about their symptoms or illness unless this was intended to help the patient identify further information needs • Training and other interventions solely targeted at clinicians to encourage them to change their consulting behaviour, for example by providing more information to patients • Intended to help patients address information needs outside consultations
Stacey et al (2012) Decision aids for people facing health treatment or screening decisions	
<i>Types of study</i>	Inclusion <ul style="list-style-type: none"> • Randomised controlled trials comparing decision aids to no intervention, usual care, alternative interventions, or a combination
<i>Types of participants</i>	Inclusion <ul style="list-style-type: none"> • People who are making decisions about screening or treatment options for themselves, for a child, or for an incapacitated significant other Exclusion <ul style="list-style-type: none"> • Situations where participants were making hypothetical choices
<i>Types of interventions</i>	Inclusion <ul style="list-style-type: none"> • Patient decision aids Exclusion <ul style="list-style-type: none"> • Interventions that focus on decisions about lifestyle changes, clinical trial entry, or general advance directives • Education programmes not geared to a specific decision • Interventions designed to promote adherence to or to elicit information consent regarding a recommended option • Decision aids that were not available to the authors in order to determine that they met the minimum criteria to qualify as a patient decision aid and their characteristics
Wetzels et al (2008) Interventions for improving older patients' involvement in primary care episodes	
<i>Types of study</i>	Inclusion <ul style="list-style-type: none"> • Randomised controlled trials • Quasi-randomised trials
<i>Types of participants</i>	Inclusion <ul style="list-style-type: none"> • Older patients (≥ 65 years) • Can include a role for patients' caregivers/family members and/or their GP in primary medical care, as long as the intention of the intervention was to improve the patient's involvement Exclusion <ul style="list-style-type: none"> • Focused solely or mainly on carers' participation • Interventions involving dentists, pharmacists, hospital nurses, community nurses, nurse practitioners and practice nurses
<i>Types of interventions</i>	Inclusion <ul style="list-style-type: none"> • Intention of increasing patients' involvement in the primary medical care consultation • Primary medical care, related to doctors or their practice • Undertaken in relation to (single) consultations (either before, during or after the consultation), or in relation to the use of health care in episodes of care • Patient-focused interventions; can take place before, during or after the patient/healthcare provider consultation Exclusion <ul style="list-style-type: none"> • Self-help groups • Focusing on structural aspects of care, for example the management of waiting times or waiting lists, appointment times, or length of consultations • Disease specific interventions • Activities that were about prevention or health promotion rather than involvement

Additional Appendix 4.1

BCW Taxonomy (v1): 93 hierarchically-clustered techniques

<p>1. Goals and planning</p> <p>1.1 Goal setting (behaviour) 1.2 Problem solving 1.3 Goal setting (outcome) 1.4 Action planning 1.5 Review behaviour goal(s) 1.6 Discrepancy between current behaviour goal 1.7 Review outcome goal(s) 1.8 Behavioural contract 1.9 Commitment</p> <p>2. Feedback and monitoring</p> <p>2.1 Monitoring of behaviour by others without feedback 2.2 Feedback on behaviour 2.3 Self-monitoring of behaviour 2.4 Self-monitoring of outcome(s) of behaviour 2.5 Monitoring of outcome(s) of behaviour without feedback 2.6 Biofeedback 2.7 Feedback on outcome(s) of behaviour</p> <p>3. Social support</p> <p>3.1 Social support (unspecified) 3.2 Social support (practical) 3.3 Social support (emotional)</p> <p>4. Shaping knowledge</p> <p>4.1 Instruction on how to perform the behaviour 4.2 Information about antecedents 4.3 Re-attribution 4.4 Behavioural experiments</p> <p>5. Natural consequences</p> <p>5.1 Information about health consequences 5.2 Salience of consequences 5.3 Information about social and env. consequences 5.4 Monitoring of emotional consequences 5.5 Anticipated regret 5.6 Information about emotional consequences</p>	<p>6. Comparison of behaviour</p> <p>6.1 Demonstration of the behaviour 6.2 Social comparison 6.3 Information about others' approval</p> <p>7. Associations</p> <p>7.1 Prompts/cues 7.2 Cue signalling reward 7.3 Reduce prompts/cues 7.4 Remove access to the reward 7.5 Remove aversive stimulus 7.6 Satiation 7.7 Exposure 7.8 Associative learning</p> <p>8. Repetition and substitution</p> <p>8.1 Behavioural practice/rehearsal 8.2 Behaviour substitution 8.3 Habit formation 8.4 Habit reversal 8.5 Overcorrection 8.6 Generalisation of target behaviour 8.7 Graded tasks</p> <p>9. Comparison of outcomes</p> <p>9.1 Credible source 9.2 Pros and cons 9.3 Comparative imagining of future outcomes</p> <p>10. Reward and threat</p> <p>10.1 Material incentive (beh.) 10.2 Material reward (beh.) 10.3 Non-specific reward 10.4 Social reward 10.5 Social incentive 10.6 Non-specific incentive 10.7 Self-incentive 10.8 Incentive (outcome) 10.9 Self-reward 10.10 Reward (outcome) 10.11 Future punishment</p> <p>11. Regulation</p> <p>11.1 Pharmacological support 11.2 Reduce negative emotions 11.3 Conserving mental resources 11.4 Paradoxical instructions</p>	<p>12. Antecedents</p> <p>12.1 Restructuring the physical environment 12.2 Restructuring the social environment 12.3 Avoidance/reducing exposure to cues for the behaviour 12.4 Distraction 12.5 Adding objects to the environment 12.6 Body changes</p> <p>13. Identity</p> <p>13.1 Identification of self as role model 13.2 Framing/reframing 13.3 Incompatible beliefs 13.4 Valued self-identity 13.5 Identity associated with changed behaviour</p> <p>14. Scheduled consequences</p> <p>14.1 Behaviour cost 14.2 Punishment 14.3 Remove reward 14.4 Reward approximation 14.5 Rewarding completion 14.6 Situation-specific reward</p> <p>15. Self-belief</p> <p>15.1 Verbal persuasion about capability 15.2 Mental rehearsal of successful performance 15.3 Focus on past success 15.4 Self-talk</p> <p>16. Covert learning</p> <p>16.1 Imaginary punishment 16.2 Imaginary reward 16.3 Vicarious consequences</p>
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Additional Appendix 4.3

BCW Taxonomy (v1): Definitions of and coding instructions for techniques used in the intervention

Label		Definition
1. Goals and planning		
1.4	Action planning	Prompt detailed planning of performance of the behaviour (must include at least one of context, frequency, duration, and intensity). Context may be environmental (physical or social) or internal (physical, emotional, or cognitive) (includes ‘implementation intentions’). <i>Note: evidence of action planning does not necessarily imply goal setting, only code latter if sufficient evidence.</i>
2. Feedback and monitoring		
2.3	Self-monitoring of behaviour	Establish a method for the person to monitor and record their behaviour(s) as part of a behaviour change strategy. <i>Note: if monitoring is part of data collection procedure rather than a strategy aimed at changing behaviour, do not code; if monitoring of outcome of behaviour, code ‘2.4 Self-monitoring of outcome(s) of behaviour(s)’; if monitoring is by someone else (without feedback), code ‘2.1 Monitoring of behaviour by others without feedback’.</i>
3. Social support		
3.1	Social support (unspecified)	Advise on, arrange or provide social support (e.g. from friends, relatives, colleagues, ‘buddies’ or staff) or non-contingent praise or reward for performance of the behaviour. It includes encouragement and counselling, but only when it is directed at the behaviour. <i>Note: attending a group class and/or mention of ‘follow-up’ does not necessarily apply this BCT, support must be explicitly mentioned; if practical, code ‘3.2 Social support (practical)’; if emotional, code ‘3.3 Social support (emotional)’.</i> Includes ‘motivational interviewing’ and ‘cognitive behavioural therapy’.
3.3	Social support (emotional)	Advise on, arrange, or provide emotional social support (e.g. from friends, relatives, colleagues, ‘buddies’ or staff) for performance of the behaviour. <i>Note: if practical, code ‘3.2 Social support (practical)’; if unspecified, code ‘3.1 Social support (unspecified)’.</i>
4. Shaping knowledge		
4.1	Instruction on how to perform behaviour	Advise or agree on how to perform the behaviour (includes ‘skills training’). <i>Note: when the person attends classes such as exercise or cookery, code ‘4.1 Instruction on how to perform the behaviour’, ‘8.1 Behavioural practice/rehearsal’ and ‘6.1 Demonstration of behaviour’.</i>

5. Natural consequences		
5.1	Information about health consequences	Provide information (e.g. written, verbal, visual) about health consequences of performing the behaviour. <i>Note: consequences can be for any target, not just the recipient(s) of the intervention; emphasising importance of consequences is not sufficient; if information about emotional consequences, code '5.6 Information about emotional consequences'; if about social, environmental or unspecified consequences code '5.3 Information about social and environmental consequences'.</i>
6. Comparison of behaviour		
6.2	Social comparison	Draw attention to others' performance to allow comparison with the person's own performance. <i>Note: being in a group setting does not necessarily mean that social comparison is actually taking place.</i>
6.3	Information about others' approval	Provide information about what other people think about the behaviour. The information clarifies whether others will like, approve, or disapprove of what the person is doing or will do.
7. Associations		
7.1	Prompts / cues	Introduce or define environmental or social stimulus with the purpose of prompting or cueing the behaviour. The prompt or cue would normally occur at the time or place of performance. <i>Note: when a stimulus is linked to a specific action in an if-then plan including one or more of frequency, duration or intensity also code '1.4 Action planning'.</i>
9. Comparison of outcomes		
9.1	Credible source	Present verbal or visual communication from a credible source in favour of or against the behaviour. <i>Note: code this BCT if source generally agreed on as credible e.g. health professionals, celebrities or words used to indicate expertise or leader in field and if the communication has the aim of persuading; if information about health consequences, also code '5.1 Information about health consequences'; if about emotional consequences, also code '5.6 Information about emotional consequences'; if about social environmental or unspecified consequences, also code '5.3 Information about social and environmental consequences'.</i>
12. Antecedents		
12.2	Restructuring the social environment	Change, or advise to change the social environment in order to facilitate performance of the wanted behaviour or create barriers to the unwanted behaviour (other than prompts/cues, rewards and punishments). <i>Note: this may also involve '12.3 Avoidance/reducing exposure to cues for the behaviour'; is also restructuring of the physical environment, also code '12.1 Restructuring the physical environment'.</i>
12.5	Adding objects to the environment	Add objects to the environment in order to facilitate performance of the behaviour.

		<i>Note: Provision of information (e.g. written, verbal, visual) in a booklet or leaflet is insufficient. If this is accompanied by social support, also code '3.2 Social support (practical)'; if the environment is changed beyond the addition of objects, also code '12.1 Restructuring the physical environment'.</i>
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Additional Appendix 5.1 – Patient interview guide for pre-testing

Introduction to the research project and aims of the interview

‘Thank you very much for agreeing to participate in this interview. By participating, you are helping us to design a booklet that will be sent to patients before their healthcare appointments.’

Anonymity and approvals

‘The interview will last between 30 and 60 minutes. I am recording the interview so that I have a record of the feedback that you provide, and so I can use this to improve the booklet. Your name will remain anonymous and all of the information collected during the interview will be kept strictly confidential. The research project has been approved by the South East Wales Research Ethics Committee’

‘Before we start, do you have any questions about this interview and it’s aim, or is there anything you would like me to explain in more detail? If at any point during the interview you would like to stop, please let me know and I will stop the recording’.

Interview

‘Throughout the interview, I will ask you some questions about the booklet that I sent to you in the post. If you made any notes/comments on the booklet before I arrived, please feel free to feed this back to me’ [hand a copy of the booklet to the patient/encourage them to locate the version they have made notes on]

‘Firstly, I’m going to ask you what you thought about the...’

A. OVERALL PURPOSE OF THE BOOKLET			
1.	What were your first impressions when you read the booklet?	Positive / negative / neutral?	
2. Social influences			
2.1	How did the booklet make you feel about patients being involved in healthcare decisions with clinicians? How has this changed since reading the booklet?	<i>Did the booklet make you feel that it is acceptable/okay to be involved in decisions about your healthcare?</i> <i>Did it make you feel that other patients usually get involved in decision-making?</i>	
2.2a	Can you tell me why it made you feel that way? / Are there any specific parts of the booklet that made you feel like that?	<i>'I'm still not sure' section</i> <i>Infographic on page 2</i>	
2.2b	Could these be improved in any way? Anything else that could be included?		
3. Social and professional role & identity			
3.1	Do you think that the booklet explained why patients and clinicians need to work together?		
3.2	Has the booklet influenced how you feel about how patients should behave in a healthcare appointment? (How has this changed since reading the booklet?)		
3.3a	Are there any specific parts of the booklet that were more useful at explaining these roles/changing how you felt about these roles?	<i>'Why should I get involved?'</i> <i>'What will I have to do?'</i>	
3.3b	Could these be improved in any way? Anything else that could be included?		
4. Beliefs about capabilities			
4.1a	Thinking about making a healthcare decision, how did the booklet make you feel about patients' own personal preferences and values? (How has this changed since reading the booklet?)	<i>Did the booklet highlight the importance of patients' personal preferences and values in the decision-making process?</i>	

4.1b	Are there any specific parts of the booklet that covered this?	<i>'Why should I get involved?'</i> <i>'I'm still not sure...'</i> <i>'What can help me get more involved?'</i>	
4.2a	Did the booklet help you feel more confident to take part in decision-making about your healthcare? (or if already confident, do they think it will help other patients?)		
4.2b	Which parts helped you to feel more confident? (Would help other patients?)	<i>'What can help me get more involved?'</i> <i>Appointment checklist</i>	
4.3	Could these be improved in any way? Anything else that could be included?		
5. Beliefs about consequences			
5.1	Who do you think has written this booklet?	<i>Who has written it?</i> <i>Who is giving the message?</i>	
5.2	How did the booklet make you feel about clinicians' attitudes towards patient involvement in decisions?	<i>Do you think clinicians want patients to be involved? Did the booklet give you permission to be involved?</i>	
5.3	How did the booklet make you feel about the consequences of being involved in decision making? Has this changed since reading the booklet?	<i>Mainly positive / negative / neutral</i>	
5.4a	Are there any specific parts of the booklet that covered clinicians attitudes towards patient involvement / consequences of being involved?	<i>'I'm still not sure...'</i> section	
5.4b	Could these be improved in any way? Anything else that could be included?		
6. Knowledge			
6.1a	Did the booklet help you to know what to expect from a healthcare appointment, if you were asked to be involved in making a decision?		
6.1b	Did it help you to understand why choices sometimes exist in healthcare?		
6.2a	Are the any specific parts of the booklet that were more useful than others in helping you know what to expect/understanding why choices exist?		

6.2b	Could these be improved in any way? Anything else that could be included?		
7. Other			
7.	Are there any parts of the booklet that you particularly like / dislike? Which ones? Why?		
<i>'I'm now going to ask you some questions about the format and design'</i>			
B. FORMAT & DESIGN			
8.	What do you think about the overall design of the booklet?	<i>Colour scheme, Font type, Size of text, Length Size of booklet</i>	
9.	What do you think about the illustrations and character design?	<i>Representative, Style</i>	
10.	Did you find that the booklet was easy to use and understand?	<i>Is the information clearly presented? Is the amount of text right (too much or too little?) Anything that we can cut-out without losing key messages/any repetition?</i>	
11.	Do you think that a booklet is an appropriate way to present this information to patients?		
12.	What other ways could we present this information and the tools (checklist/notepad) to patients?	<i>Different formats e.g. tablet apps, phone apps, website</i>	
13.	What do you think about the title/name of the booklet, 'Your health, Your choice'? Do you have any alternative suggestions?		
14.	Thinking about being a patient, when would you like to receive the booklet? How?	<i>Just before appointment, before you arrive at the clinic? Via post etc?</i>	
<i>'Thank you very much for you time and your participation'</i>			

Additional Appendix 5.2 – Analysis framework for patient interview data

Social influences and perceived role in consultations	Beliefs about Capabilities	Beliefs about consequences	Knowledge	Environmental context & resources	Others
Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours. Related to perceived social norms, influences from other individuals	Acceptance of the truth, reality, or validity about ability to take part in SDM	Acceptance of the truth, reality, or validity about outcomes of participating in SDM	An awareness of the existence of SDM	Any circumstance of a person's situation or environment that discourages or encourages the use of SDM	
Certain groups of population should not or cannot be involved in SDM	'Doctor knows best', recognising patient contribution	Overcoming perceived negative consequences	Knowledge of existence of choice	How the intervention could be delivered	Key message
Attitudes related to the perception that certain groups of the population might find it more difficult to be involved in SDM, or should not be involved in SDM (e.g. older/younger age, lower level of education/certain ethnic groups)	Attitudes relating to 'Doctor knows best', patients have inferior knowledge or recognising patient contribution to the decision-making process	Overcoming perceived negative consequences of being involved in decision-making and promoting perceived positive outcomes of being involved in decision-making	Knowledge about the existence of choice in healthcare decision-making	How the intervention could be delivered (e.g. format / structure of appointment)	Participants' perceptions of key booklet message
Changing views on perceived acceptability of being involved in healthcare decisions (social norm)	Patients feeling capable of understanding information	Challenging perceptions right and wrong decisions	Knowledge about choices available	When intervention could be delivered	Continuity in care
Attitudes related to the perceived acceptability of being involved in healthcare decision-making (i.e. changing the social norm about patient involvement in healthcare decisions)	Patients believing that they are capable of understanding the information about their treatment options	Challenging perception that there are right and wrong decisions	Knowledge about the choices available	When the intervention could be delivered (e.g. timing before consultation)	Perceptions related to continuity in care e.g. seeing the same doctor / familiarity of the doctor
Changing expectation that clinicians should make		Perceived benefit to clinicians	Knowledge about what to expect	Who intervention could be delivered by	Skills of clinician

<p>decisions</p> <p>Changing patients expectation that clinicians should make healthcare decisions on their behalf, and challenging the belief that patients are not entitled to a choice</p>		<p>Perceived benefit to clinicians of patient involvement</p>	<p>Knowledge about what to expect from a SDM consultation with a clinician</p>	<p>Who the intervention could be delivered by (e.g. by clinical team)</p>	<p>Factors relating to the skills of the clinician</p>
<p>Changing perception that clinicians don't want patients involved</p> <p>Attitudes related to the perception that clinicians do not want patients involved in healthcare decision-making</p>		<p>Impact on clinicians</p> <p>Participants' perceptions of the adverse impact it might have on the clinicians providing care or the organisation more broadly</p>		<p>Use of interactive elements</p> <p>Use of the booklet's interactive elements (e.g. checklist / notepad)</p>	<p>Examples of patient involvement</p> <p>Examples of patient involvement in decision-making (self or others)</p>
<p>Explicit permission to participate</p> <p>Perceiving that there is explicit permission to participate from either the clinician(s) or the healthcare organisation more broadly</p>				<p>Supportive environment</p> <p>Supportive clinicians / clinical team / healthcare organisation</p>	<p>Avoiding responsibility</p> <p>Perceptions that approach might be seen as clinicians or the organisation more broadly avoiding responsibility</p>
<p>Seeking decision support from others</p> <p>Realising that other people can be involved and support the decision-making process (e.g. family, friends, other clinicians)</p>					
<p>Comparison to other patients</p> <p>Participants relating to other patients and making social comparisons</p>					

Additional Appendix 5.3 – Clinician interview guide for pre-testing

Introduction to the research project and aims of the interview

‘Thank you very much for agreeing to participate in this interview. By participating, you are helping us to design a booklet that will be sent to patients before their healthcare appointments. The aim of the booklet is to prepare patients to become more involved in healthcare decisions.’

Anonymity and approvals

‘The interview will last around 30 minutes. I am recording the interview so that I have a record of the feedback that you provide, and so I can use this to improve the booklet. Your name will remain anonymous and all of the information collected during the interview will be kept strictly confidential. The research project has been approved by the South East Wales Research Ethics Committee’

‘Before we start, do you have any questions about this interview and it’s aim, or is there anything you would like me to explain in more detail? If at any point during the interview you would like to stop, please let me know and I will stop the recording’.

Interview

‘Throughout the interview, I will ask you some questions about the booklet that I sent to you before the interview. If you made any notes/comments on the booklet before I arrived, please feel free to feed this back to me’ [hand a copy of the booklet to the participant/encourage them to locate the version they have made notes on]

A. OVERALL PURPOSE OF THE BOOKLET			
1.	What were your first impressions when you read the booklet?	<i>Positive / negative / neutral?</i>	
2.	What did you think the main purpose of the booklet was?	<i>The purpose of the booklet is to encourage patients to become more involved in healthcare decisions during consultations. Do you think that this was obvious?</i>	
3.	What would you say were the key messages for you?		
4.	Do you think that the booklet would help [your] patients? In what way? Do you think that the booklet could help your organisation/team? In what way?	<i>What are the advantages of patients using the booklet? Are there any disadvantages of sending this booklet?</i>	
5.	What do you think about the title / name of the booklet, 'Your health, Your choice'? Do you have any alternative suggestions?		
6.	Thinking about your own clinical team/organisation, how do you see this booklet being used?	<i>When do you see this booklet being given to patients? Just before appointment, before you arrive at the clinic? Via post etc?</i>	
7.	Would this work well with [the] existing clinical pathway[s]?	<i>What might be the potential problems with this process? What changes might need to be made?</i>	
<i>I'm now going to ask you some questions about the format and design'</i>			
B. FORMAT & DESIGN			
8.	What do you think about the overall design of the booklet?	<i>Colour scheme, Font type, Size of text, Length Size of booklet</i>	
9.	What do you think about the illustrations and character design?	<i>Representative, Style</i>	
10.	Did you find that the booklet was easy to use and understand?	<i>Is the information clearly presented? Is the amount of text right (too much or too little?) Anything that we can cut-out without losing key</i>	

		<i>messages/any repetition? Is the language used clear? (Too formal etc)</i>	
11.	Do you think that a booklet is an appropriate way to present this information to patients?		
12.	What other ways could we present this information and the tools (checklist/notepad) to patients?	<i>Different formats e.g. tablet apps, phone apps, website</i>	
<i>'I'm now going to ask you some questions about specific elements of the booklet'</i>			
C. SPECIFIC ELEMENTS			
13.	Are there any parts of the booklet that you particularly like? Which ones? Why?		
14.	Are there any parts of the booklet that you particularly dislike? Which ones? Why?	<i>What do you think of the 'I'm still not sure' section? What do you think of the 'What will I have to do?' section? What do you think of the 'What can help me get more involved?' section? What do you think of the appointment checklist?</i>	
<i>'And to finish off...'</i>			
15.	Do you think that there is any important information missing from the booklet?		
16.	Do you have any other suggestions for improvement?		
<i>'Thank you very much for you time and your participation'</i>			

Additional Appendix 6.1 Process Evaluation – patient interview guide

Prologue

1. Introduce yourself, explain where you are from, ensure they are comfortable etc.
2. Check understanding for reason of meeting, explain role of researcher, give opportunity to ask questions
3. Set focus of the interview, overview of what I will ask, show booklet [hand copy]
4. Explain that interview will be recorded
5. Recap consent form, give double signed copy, switch on recording equipment

INTERVIEW SCHEDULE

Orientation to the booklet for main focus of discussion

A. Background / Care pathway stage

1. Have you attended the breast clinic for your initial appointment? [understand what stage you are at with your healthcare appointments]
 - a. If yes, have you been called back for another appointment
 - b. If yes, have you received test results?

B. Implementation – process, dose, reach

1. Did the booklet arrive before your appointment at the breast clinic? If yes, roughly how long before your appointment did you receive it? [*ask if necessary*]
2. Did you read the booklet when you received it in the post?
 - a) Did you read it straight away?
 - b) Would you say you read the entire booklet or only some parts of the booklet [which parts?]
 - c) How long did it take you to read it?
 - d) Did you share the booklet with anyone else? Who? How did you share this?
 - e) Did you make any notes on the booklet?
 - f) Did you use the notepad / checklist? If yes, how?
 - g) Did you look for any further information, after reading the booklet?
3. How easy of difficult did you find the booklet to read and understand? [Did it make sense?]

C. *Mechanisms of impact*

1. What do you think is the purpose of the booklet?
2. Why do you think the Breast Care Centre are sending the booklets to patients before their appointments?

Knowledge

Check existing knowledge for each question

3. Did the booklet help you to understand what it means to be involved in making a decision with a clinician?
 - a. Can you describe what this means to you?
4. Did the booklet explain *why* patients should become involved in healthcare decisions together with clinicians?
 - b. Can you explain why you think it is important that patients are involved in their healthcare decisions? [What does the patient contribute?]
5. Did the booklet explain *what to expect* if a clinician asks you to be involved in a healthcare decision?
 - c. Can you describe the key steps a clinician might go through if you have a healthcare decision to make together? [process]
6. Do you think the booklet enhanced your knowledge about shared decision-making, or was it something you already knew about?
7. After reading the booklet, do you feel that you know enough about shared decision-making to take part in future decisions? If no, is there anything else you would like to know beforehand?

Social / professional role and identity

8. Do you think it is part of the patient's role to take part in decision-making? Why?
 - a. Has your view changed since reading the booklet?
9. As a patient, do you feel that it is okay to ask the clinician questions?
 - a. Has your view changed since reading the booklet?

Beliefs about capabilities

10. For you personally, would you say it would be possible or impossible to make a decision together with a clinician?

- a. Did the booklet have any influence on how you feel?

Thinking ahead to your next appointment with a doctor or nurse, if you were told that you had healthcare choices;

11. How confident are you that you would be able to understand the information that is given to you about the choices?
12. How confident are you that you can take part in the decision-making process with a clinician?
- d. Has the booklet helped you to feel more confident in any way?

Beliefs about consequences

13. How did the booklet make you *feel* about patients being involved in healthcare decisions with their clinicians?
14. After reading the booklet, do you feel that there are benefits for patients who take part in their healthcare decisions? Can you describe these please?
15. After reading the booklet, do you think that there are disadvantages for patients becoming more involved? Can you describe these please?
16. After reading the booklet, do you feel that there are disadvantages for patients who do not take part in their healthcare decisions? Can you describe these please?
17. For you personally, do you think that being involved in your healthcare decisions:
 - a. would be a good thing, or a bad thing? Why?

Social influences

18. Do you think that most other patients would want to take part in a shared decision?
 - e. Has this view changed since reading the booklet?
19. Do you think that most clinicians want patients to become more involved in decision-making?
 - a. Has the booklet influenced how you feel about this? How?
20. Do you think that the local health board more broadly wants patients to become more involved in decision-making?
 - a. Has the booklet influenced how you feel about this? How?
21. As a patient, are there any other people that you would involve in your decision-making? How would you involve them? How would this help you?

D. Overall perceptions & intended future behaviour

1. Was the booklet useful for you personally? In what way?
2. Did it raise any questions / concerns? Do you have any unanswered questions?
3. What impact do you think reading this booklet would have on the conversation that you had with the nurse or consultant at the Breast Care Centre?

Ask you to think ahead to your next healthcare appointment. This could be with any healthcare professional:

- a) Do you think that you would ask the clinician if you have treatment choices?
 - b) If you have choices, do you think that you would ask the clinician to explain the positive and negative features of the options? [if not described]
 - c) Do you think you would tell the clinician what matters most to you / your personal preferences?
4. Is there anything that would stop you from becoming more involved in decision-making?
 5. Is there anything that would help you to become more involved in the decision-making?

E. Design and future use

1. Were there any parts of the booklet that you liked / disliked?
2. Are there any parts of the booklet that you would like to see changed?
 - [font, language, colour scheme, graphic design, characters, information clarity]
3. In what way do you think the booklet could help other patients if they have an appointment coming up?
4. Do you see any disadvantages of sending this booklet to patients before their appointments?
5. If there health board were to roll this out, when would you like to receive it in future (before appointment, during appointment, after appointment)?
6. It is currently in a booklet format; do you think it could be created in any other formats?

TO FINISH

Age:

Summary of results?

Additional Appendix 6.2 – Analysis framework for patient pilot-testing: assessing mechanisms of change

TDF Domains					
Knowledge	Professional / social role & identity	Beliefs about capabilities	Beliefs about consequences	Social influences	Other themes
Knowledge about the existence of SDM	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting	Acceptance of the truth, reality, or validity about ability to take part in SDM	Acceptance of the truth, reality, or validity about outcomes of participating in SDM	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours (related to perceived social norms, influences from other individuals)	
Existence of healthcare choices Awareness about the existence of healthcare choices and what it means	Acceptability of involvement Patients' perceived acceptability of being actively involved in the decision making process	Recognising patients' unique expertise / capabilities Patients' recognising the importance and value of the patients' unique expertise that they bring to the decision-making process.	Advantages of patient involvement Perceived advantages for patients of being more involved in the SDM process	Other patients Perceptions about other patients' desire to become more involved in healthcare decisions	Barriers to SDM Perceived barriers to becoming more involved in healthcare decisions with a clinician
Purpose of booklet Patients' perceptions of the purpose of the booklet			Disadvantages of patient involvement Perceived disadvantages of patients being more involved in the SDM process	Clinicians' beliefs Perceptions about whether clinicians' want patients to become more involved in healthcare decisions	Facilitators of SDM Perceived facilitators of becoming more involved in healthcare decisions with a clinician
				Health organisation's beliefs Perceptions about whether the broader health organisation want patients to become more involved in healthcare decisions	Intended future behaviour The perceived impact of the booklet on intended future behaviour in healthcare consultations

