Template Review Summary: RESPECT_Form-v0 (Revision: 5) (Summary view of 6 reviews)

RESPECT_Form-v0

Header

Template Name	RESPECT_Form-v0	
Meta Data	**Template ID:** a8e84871-b1c0-428b-90a7-37c2961c9d10 **MetaDataSet:Sample Set :** MetaDataSet:Sample Set	
Purpose	Representing the dataset for capture, reporting and auditing the details of ReSPECT.	

Data

ReSPECT Form Composition	Document to communicate details of ReSPECT (Recommended Summary Plan for Emergency Care and Treatment).		*Juliet Spiller (04-Jan-2018)* I'm not sure 'details of ReSPECT' is right - the form records the summary of the outcome of the ReSEPCT process which is one or more conversations. Document to communicate relevant patient information and summary recommendations from ReSEPCT process? ***Editor Feedback*** @Juliet: accept - we'll change the wording
2. Summary of relevant information Section	Heading containing summary of relevant information for the ReSPECT plan.		*Juliet Spiller (04-Jan-2018)* Nit-picking again but...process rather than plan? (Plan is within ReSPECT anyway) *Zoe Fritz (04-Jan-2018)* this section is a chance for the clinician and patient to see if they have shared understanding of what the most important diagnoses/ social facotrs are - it should not just be an inported problem list. The completion of it has a role in setting up the conversation. ***Editor Feedback*** @Juliet: accept - we'll change the wording @Zoe: we have taken this on board. The narrative summary below is intended to capture the outcome of that conversation between clinician and patient. The following sections allow for optional more structured capture of diagnosis information, however, this clearly does require further discussion.
2.0 Relevant information	Narrative and structured details of		

Section	relevant information.		
Narrative summary Text	Including diagnosis and reasons for the preferences and recommendations recorded.		*Peter-Marc Fortune (02-Jan-2018)* Should we consider a restriction on how much text can be included here? % pages of A$ text wouldn't be helpful!! *Juliet Spiller (04-Jan-2018)* fine *Paul Miller (04-Jan-2018)* I am anxious that this will conflict with any structured data elsewhere captured. It is not really a summary but an 'any additional information' field as the summary is established by the data elsewhere recorded. It would be better at the end of the form. risk is people put everything in here and make no use of structured data fields. Need to ask and clarify 'what is this for?' ***Editor Feedback*** @Peter-Marc: we'd expect this to be general guidance rather than a fixed limit. @Paul: you'll appreciate there is a divergence of reviewer opinion which needs to be thrashed out. @All: we'll work on the description to try and capture the multiple purposes of this narrative, e.g. overview, snapshot
Interpreter required Boolean	Statement whether interpreter is required.		*Ian Thompson (01-Jan-2018)* Does this need to capture additional details of what interpreter is needed or is this intended to be held elsewhere in the medical record? e.g. Language? Remembering that interpreter is just one of Additional Support Needs that may well be held elsewhere in a record ? should we include the ASN construct here - does that mean RePSECT needs to change? *Peter-Marc Fortune (02-Jan-2018)* I think its useful to capture this - surely if the answer is yes we should capture the language! *Juliet Spiller (04-Jan-2018)* does this link automatically include the language needed? *Paul Miller (04-Jan-2018)* Should have terminology binding as well as comment text. Could be modelled as 'languages spoken' Read V2 "9NU.. Need for interpreter" and children is also in SNOMED CT "315594003 |Interpreter needed (finding)|" Presentation layer could handle

			the Boolean interpretation. At very least would have 'Needed' and 'Not needed' as codes. ***Editor Feedback*** @all: the underlying archetype has the required fields for this, we'll relax the constraints and line up with national NHS guidance. That might be too detailed but we can tighten up again if necessary. @ian: see comment below re ASN
Other communication needs Text	Details of other communication needs such as communication aids.		*Ian Thompson (01-Jan-2018)* See comment above about additional support needs. *Peter-Marc Fortune (02-Jan-2018)* I think this is helpful *Juliet Spiller (04-Jan-2018)* I like this as separate from narrative field as it will be overlooked otherwise *Paul Miller (04-Jan-2018)* This sort of ties into the Additional Special Needs work and agree this will / should be expanded on in the future so for now just have as text. It involved sight and hearing issues, as well as learning disabilities so is potentially very complex and not in scope to model formally here. ***Editor Feedback*** @all: agreed, we should reference national standards on this. @Paul: agree, this might be too complex and we definitely need to keep free text as fall-back, but we should put in at least some structure as long as we make it optional.
2.1 Principal diagnosis Section	Details of the principal diagnosis leading to the need for a ReSPECT form.		*Ian Thompson (01-Jan-2018)* It would be preferable to have the possibility of including coded diagnosis data where this exists, but there needs to be a alternative option to cope with scenarios where it does not or where adding it would interrupt the respect completion process. *Peter-Marc Fortune (02-Jan-2018)* See comments below *Zoe Fritz (04-Jan-2018)* so I understand from our conversation that it may be helpful to import diagnostic codes, for audit etc purposes - I like the idea of being able to select some of the relevant ones from a list. I HATE the idea of having it all imported *Paul Miller (04-Jan-2018)* It may be though that this data

			is pulled from another system to populate so is important is not just narrative in Section 2. ***Editor Feedback*** @All: this is definitely optional and Zoe's idea of selective import is the ideal approach but would depend on specific application. @Ian - to be discussed
ReSPECT principal diagnosis Evaluation	The principal diagnosis leading to the need for a ReSPECT form.		*Ian Thompson (01-Jan-2018)* AS above would prefer coded option but recognise this may not always be available. if there is a techie solution to construct something the could be coded and could also include some un coded free text that would satisfy both world views. *Juliet Spiller (04-Jan-2018)* I'm not understanding the need for 4 separate diagnosis fields. I was thinking we would have one main relevant diagnosis (coded) and a linked narrative box as you have in the two boxes below. *Zoe Fritz (04-Jan-2018)* not sure I understand the difference between this and the above ***Editor Feedback*** @Juliet and Zoe: the first two of these fields are headings - you would not see these in the app. @Ian: see previous comment
Principal diagnosis Text Mandatory	The name of the principal diagnosis, preferrably coded, e.g. 'Bronchial carcinoma'.		*Ian Thompson (01-Jan-2018)* Same comment about possibility of having coded diagnosis applies there. *Peter-Marc Fortune (02-Jan-2018)* 'Principle' may not always be a useful term as many patients with complex conditions may have several "Key" diagnoses. I fear that the inference of "Principle diagnosis" is that which is most life limiting - something we are trying to avoid! Modify to allow a number of "Key diagnosis" *Paul Miller (04-Jan-2018)* I think this should *always* be coded. I cannot see any scenario where a terminal condition is not going to have a corresponding SNOMED CT concept. ***Editor Feedback*** @Peter-Marc: we can rename this and make it multiple occurrence. @Paul: this is obviously true in General Practice, but may not

			always be possible in other settings.
Clinical description Text	Narrative description about the problem or diagnosis. Comment: Use to provide background and context, including evolution, episodes or exacerbations, progress and any other relevant details, about the problem or diagnosis.		*Zoe Fritz (04-Jan-2018)* I am not sure this is needed as a separate box - my view would be have one option to tick whatever diagnoses the clinician feels are relevant and then have the narrative summary - in other words only two fields to complete *Paul Miller (04-Jan-2018)* Here is where clarification of the diagnosis or the human readable / lay person interpretation of that can be included. Maybe we need another field for 'Patient / Carer's name for condition'? ***Editor Feedback*** @Zoe: a single narrative box for all diagnoses would be possible but most GP system record text per condition. to be discussed further
2.2 Other significant conditions Section	Details of other significant conditions relevant to the ReSPECT form.		*Ian Thompson (01-Jan-2018)* as comment in principale diagnosis, coded where possible otherwise free text. *Peter-Marc Fortune (02-Jan-2018)* This remains relevant even with my comments above. e.g Patient may have key diagnosis 1 of Cerebral Palsy, 2 or Chronic Lung Disease but also have a significant condition of eczema *Juliet Spiller (04-Jan-2018)* happy with this in addition to the two boxes above *Paul Miller (04-Jan-2018)* Sure, again should be coded data especially if being populated through interop with other systems.
ReSPECT other significant condition Evaluation Optional, repeating	Details of other significant conditions relevant to the ReSPECT form, e.g. Diabetes.		*Juliet Spiller (04-Jan-2018)* is this the narrative box linked with the coded field above? *Paul Miller (04-Jan-2018)* I am more ok with these not being coded tho' again any significant condition should have an available SNOMED CT concept. ***Editor Feedback*** @Juliet: yes, that's correct @Paul: see comment above about coded diagnoses outside General Practice
Other significant condition Text Mandatory	The name of other significant condition relevant to the ReSPECT form,		

	preferrable coded, e.g. 'Diabetes'.		
Clinical description Text	Narrative description about the problem or diagnosis. Comment: Use to provide background and context, including evolution, episodes or exacerbations, progress and any other relevant details, about the problem or diagnosis.		
2.3 Other relevant planning documents Section	Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.		*Peter-Marc Fortune (02-Jan-2018)* Ideally we need to include all currently recognised documents plus ability to enter details of an unclassified document. Most obvious current omission is Child & Young Person's Advance Care Plan (CYPACP): Is it possible to point one archetype at another? So if we develop one for CYPACP this could allow selection of relevant fields for inclusion? *Juliet Spiller (04-Jan-2018)* Wherever you have Advance Care Plan can you write Advance or Anticipatory Care Plan (in Scotland we use Anticipatory Care Plan nationally now) *Zoe Fritz (04-Jan-2018)* I think this would be useful to import from other databases e.g. of advance plans to refuse treatment, etc *Paul Miller (04-Jan-2018)* We maybe need a way to add 'Document type' and 'Description of document' and 'location of document' to cover all the many things that end users may want to capture here. Not sure we need to specifically model the 3 referred to in the paper form, although organ donation is probably useful. ***Editor Feedback*** @All: this feedback applies to the entire section: we can create a maximal list of all available forms and have implementation guidance for different countries/legislations. Can use clinical document naming standards for reference. Alternatively we can 'dumb it down' and have just generic links
Advance decision to	An advance decision		*Juliet Spiller (04-Jan-2018)*

refuse treatment Evaluation	to refuse treatment (ADRT) is a decision to refuse a specific treatment, made in advance by a person who has capacity to do so.		legal under MCA(2005) in E&W only
Decision status Coded Text	The state of the decision to refuse treatment.	• Advanced decision to refuse treatment signed [The subject has signed an advanced decision to refuse treatment.] • Has advance decision to refuse treatment (Mental Capacity Act 2005) [The subject has signed an advance decision to refuse treatment (Mental Capacity Act 2005).] • Has advance decision to refuse life sustaining treatment (Mental Capacity Act 2005) [The subject has signed an advance decision to refuse life sustaining treatment (Mental Capacity Act 2005).] • Advanced directive not signed [The subject has not signed and advance directive or has rescinded an early directive.]	*Juliet Spiller (04-Jan-2018)* I like the second bullet point alone. It is essential to be able to clarify if a legal ADRT document exists for E&W patients and for others if an advance directive or other ACP exists. (PS it is advance not advanced in context of advance decision) ***Editor Feedback*** @Juliet: we'll correct the typo. Let's discuss with the group whether first and third bullet points can be omitted (the fourth is needed for negation).
Special Question	**Is this detailed structure required? Will you need to query and audit explicitly on a particular status - if so, this needs to be structured.**		*Peter-Marc Fortune (02-Jan-2018)* See above - ideally all is needed is flag to full document but would be useful to include subset/all fields from ADRT archetype *Juliet Spiller (04-Jan-2018)* not needed I think - just presence of legal ADRT(MCA 2005) or Advance directive / ACP *Zoe Fritz (04-Jan-2018)* not sure - the law is different in different parts of the UK, and so I wonder whether less detail here is better, as we will get bogged down. best just to have whether one exists and where it is. *Paul Miller (04-Jan-2018)* Unless there is a universal and formalised definition of what constitutes and advance decision to rtefuse treatment then modelling it here is not required. The 4 codes refer to

			MC Acts which are different I think in Scotland. Personally I would take all that out and just include pointers to the presence of such documentation. Others would need to model the additional documents if that was wanted.
Date of decision Date/Time	The date at which the DNACPR decision was originally taken or last reviewed.		*Juliet Spiller (04-Jan-2018)* not needed *Zoe Fritz (04-Jan-2018)* ok
Location of advance directive documentation Text	The location of the original advanced directive document, either a text description or an electronic link.		*Peter-Marc Fortune (02-Jan-2018)* Is it possible to 'future proof' this by including ability to hyperlink (or equivalent) to future ADRT database? *Juliet Spiller (04-Jan-2018)* This could be location of advance directive or Anticipatory Care Plan or other - legally an advance directive (that is not a proper ADRT in E&W) is the same as an ACP document ***Editor Feedback*** @Peter-Marc: we can add a link @Juliet: we can change the description to make it more generic
Advanced care planning Admin Entry	Care planning and pathway aspects of an End of Life Care Coordination record.		*Juliet Spiller (04-Jan-2018)* Advance (not advanced) or Anticipatory care planning. Text is wrong - Presence of document that records future care planning wishes and information. *Paul Miller (04-Jan-2018)* As above for ADRT ***Editor Feedback*** @All: we'll remove this altogether.
Summary Text	Narrative description of advanced care planning decisions and recommendations.		*Juliet Spiller (04-Jan-2018)* Not needed here - just presence of and location of the document. Relevant detail from valid ACP for emergency decisions would be highlighted in Section 4 ***Editor Feedback*** @Juliet - see above comment
Organ donation preferences Admin Entry	Organ donation preferences.		*Ian Thompson (01-Jan-2018)* DO we need to capture this here separately from NHS organ Donor Register or with this just a structure to reflect entries in that? How can we ensure that in implementations of ReSPECT that bi-directional communication with the Organ Donor register(s) [not sure if there is a single UK one or 4 separate ones] to pull in existing information at the time

			ReSPECT discussion is occurring and push out data from a ResPECT process to that - we would need to ensure that consent was captures to share this and that any privacy notice including this so as not to fall foul of GDPR. However that is all more for implantation guidance that the actual data we need to store. *Peter-Marc Fortune (02-Jan-2018)* Need to capture whether discussed or not. Same comment as above re relevant documents - can we chose 'nested' archetypes and select some/all fields? *Zoe Fritz (04-Jan-2018)* I am happy to have this, but others were not *Paul Miller (04-Jan-2018)* Happy enough with this if it is building on currently implemented models but again maybe all we need to do is point at something else for now, and can become more structured if / when this is formally modelled elsewhere. Certainly would be value in having this as data in some way, both for reporting and for enabling transplant services to have better operational data. ***Editor Feedback*** @All: we'll check approach taken by organ donation register
Specific organs Choice Optional, repeating	Description of which organ or organs the subject wishes to donate.	• **Coded Text** ◦ Kidneys [The subject wishes to donate their kidneys.] ◦ Heart [The subject wishes to donate their heart.] ◦ Liver [The subject wishes to donate their liver.] ◦ Pancreas [The subject wishes to donate their pancreas.] ◦ Small bowel [The subject wishes to donate their small bowel.]	*Ian Thompson (01-Jan-2018)* How well does this match with NHS organ donor register structures? *Peter-Marc Fortune (02-Jan-2018)* If including this level of info need to include tissue donation too. *Juliet Spiller (04-Jan-2018)* happy ***Editor Feedback*** @All: see above comment

		◦ Lungs [The subject wishes to donate their lungs.] ◦ Corneas [The subject wishes to donate their corneas.] ◦ Skin [The subject wishes to donate their skin.] ◦ Tissue [The subject wishes to donate tissue.] • **Text**	
All organs Boolean	Statement whether the subject wishes to donate all organs.		
3. Personal preferences Section	Details of personal preferences to guide this ReSPECT plan (where the person has capacity).		
Preferred priorities of care Evaluation Optional, repeating	The subject's preferred priorities of care and special requests.		*Juliet Spiller (04-Jan-2018)* priorities for care and "What matters" ***Editor Feedback*** @Juliet: we'll change the wording
Care priority scale Count	Indication on a scale of 1 - 10 of where priority for care should be. 1 indicates absolute priority on sustaining life (even at the expense of comfort) and 10 indicates absolute priority on comfort (even at the expense of sustaining life).	1..10	*Ian Thompson (01-Jan-2018)* As I've not been involved in the development of RePSCT I'm not sure what the practical implementations of this would be if the scale is limited in steps by the 1...10 what does a mark at a particular point mean in terms of what treatments are offered or not or is it more a general feel. Happy to discuss out with review process on a phone call with someone. *Paul Miller (04-Jan-2018)* Needs a way to record ambivalent, 5.5? Something right in the middle and not more to one or other side. ***Editor Feedback*** @Ian: it's intended to capture the general impression and not to trigger any specific action. @Paul: see below, more granular support this.
Special Question	**On the UI this can be represented as a Visual Analogue Scale - is 1-10 appropriate or**		*Peter-Marc Fortune (02-Jan-2018)*

	should it be more granular (e.g. 1-100)?		I think 1-10 should be adequate, however desirability of a system accurately placing a visual mark exactly as placed by the patient may call for finer scale. Is there a disadvantage to using a 1-50 (or 1-100) range? *Catherine Baldock (03-Jan-2018)* Is a score necessary, there is no numbering on the form. Can this be left blank or must it be completed as the paper form has this as optional *Juliet Spiller (04-Jan-2018)* Will the numbers be hidden from the person completing this electronically? If so I think 1-100 would be better to allow the mark to be placed exactly where the patient wants it and not feel tied into a number category. *Zoe Fritz (04-Jan-2018)* I think more granular - we don't want people starting to refer to patients by number " I think they were a 7" *Paul Miller (04-Jan-2018)* More increments make for a smoother scale perhaps, if someone is dragging a slider so probably 1-100 better. ***Editor Feedback*** @All - we'll change the scale to 1-100 @Catherine: the field IS optional, but if the patient does put a mark on the line, the number is required to compute the position on the line.
Care priority Text	A narrative statement by the patient on their preferred priorities of care.		*Catherine Baldock (03-Jan-2018)* This is optional. Some patients choose not to complete this - will this electronic version allow this *Juliet Spiller (04-Jan-2018)* can you add "and what would be important to them in an emergency"" *Zoe Fritz (04-Jan-2018)* Can we keep the text exactly as it was on the ReSPECT form for this bit? " Considering the above priorities, what is most important to you? (optional). ***Editor Feedback*** @Catherine: yes, this is optional and will be supported. @Juliet and Zoe: yes, we'll add the exact wording of the form.
4. Clinical recommendations Section	Details of clinical recommendations for emergency care and treatment.		*Juliet Spiller (04-Jan-2018)* Summary of rather than details ***Editor Feedback*** @Juliet: agreed, we'll change

			the wording
Clinical recommendation Evaluation	The clinician's clinical recommendation for emergency care and treatment for the ReSPECT plan.		*Juliet Spiller (04-Jan-2018)* Summary of agreed and realistic clinical recommendations for emergency care and treatment ***Editor Feedback*** @Juliet: We'll change the wording.
Focus Coded Text Optional, repeating	Focus on life-sustaining treatment or symptom control according to clinical guidance on specific interventions specified below.	• Life-sustaining treatment [Focus on life-sustaining treatment.] • Symptom control [Focus on symptom control.]	*Zoe Fritz (04-Jan-2018)* needs to be able to choose one or other - a hard stop? ***Editor Feedback*** @Zoe: it is intended to be a hard stop so only one option can be selected.
Clinical guidance on interventions Text Optional, repeating	Clinician's guidance on specific interventions that may or may not be wanted or be clinically appropriate, including being taken or admitted to hospital +/- receiving life support.		*Peter-Marc Fortune (02-Jan-2018)* An element of sub coding would be useful here. For example boolean entries for: 1 Admission to hospital 2 Admission to Intensive Care 3 Non-invasive ventilation 4 Invasive Ventilation 5 Oral Antibiotics 6 Intravenous antibiotics ...can produce more extensive list if agreed! *Juliet Spiller (04-Jan-2018)* how do we prompt brevity and clarity (bullet points?) to reflect limit of paper form box and ensure easy to print out and to read in an emergency *Paul Miller (04-Jan-2018)* There is some argument to be made for taking some of these things out and making them structured - for example preferred place of care and death both have associated SNOMED CT concepts in the UK edition that also are used in current KIS implementations. ***Editor Feedback*** @All: list of choices should go into guidance but probably not appear in the UI? Tick boxes not an option.
CPR decision Evaluation	The outcome of a clinical decision as to whether cardio-pulmonary resuscitation should be undertaken or not. This is generally referred to in UK clinical guidance as the CPR (Cardio-pulmonary resuscitation) decision.		*Juliet Spiller (04-Jan-2018)* The advance recommendation as to whether cardio-pulmonary..... ***Editor Feedback*** @Juliet: we can change the wording
CPR decision Coded Text	The clinical decision on whether cardiopulmonary resuscitation (CPR)	• CPR attempts recommended adult or child [Cardio-pulmonary	*Ian Thompson (01-Jan-2018)* There is some useful feedback from KIS about confusion by end users of the system about

	should be attempted. In some cases a clear answer may not be available to the recording clinician.	resuscitation is recommended for adult or child.] • CPR attempts not recommended adult or child. [Cardiopulmonary resuscitation is not recommended for adult or child.] • CPR decision status unknown [There is no clear information on the outcome of the CPR decision.] • For modified CPR child only [Modified CPR is recommended for child only.]	DNACPR status (which I must admit reflected the process at the time of original development, but less so now). There were also concerns that people were interpreting a CYPADM as meaning DNACPR so the modified CPR bit needs to be clearly indicated in any interface. I would question if there is a need to record status unknown or maybe it is more about end user display of status (again an implementation issue rather than a clinical content one). *Peter-Marc Fortune (02-Jan-2018)* Modified (for children) should capture modification as subsection if this option is selected *Catherine Baldock (03-Jan-2018)* CPR decision status unknown if selected must prevent the form being completed or printed. Alternatively remove this statement as an option. *Juliet Spiller (04-Jan-2018)* As above "The advance recommendation as to whether cardio-pulmonary..... I am struggling with seeing this section electronically - I think We need one more option where CPR is not recommended because it is clinically certain it would not work but not agreed or discussed with patient or family - this option must be explained in section 6 D *Zoe Fritz (04-Jan-2018)* again, a hard stop? *Paul Miller (04-Jan-2018)* Need to consider how these are coded as SNOMED CT would be best but these are different from currently available concepts. OTOH not sure we want yet more CPR concepts! Has someone worked this up from a terminological perspective? ***Editor Feedback*** @Zoe: yes, a hard stop @All: issues to discuss: 1. subcategories for Modified - yes, definitely needed 2. recording unknown or not - no, won't record unknown 3. further option to say 'not recommended but not agreed or discussed'
Date of CPR decision Date/Time	The date at which the CPR decision was originally taken or last reviewed.		*Juliet Spiller (04-Jan-2018)* not needed - same for whole form date and review. *Paul Miller (04-Jan-2018)* So we can work out original date Vs review dates simply by which one came first?

Protocol			
5. Capacity and representation Section	Details of capacity and representation at the time of completion of the ReSPECT form.		*Peter-Marc Fortune (02-Jan-2018)* Need to include "Person(s) holding parental responsibility" in this section for children. Would need to include two persons +/- social care professional *Juliet Spiller (04-Jan-2018)* the capacity yes or no option needs to come before the documentation of presence of a legal proxy
Capacity and representation Admin Entry	Details of power of attorney arrangements specific to the UK.		*Juliet Spiller (04-Jan-2018)* Document presence of appointed legal proxy arrangements (detail goes in box 8)
Special Question	**This is an existing archetype which contains more detail than the ReSPECT form. Is this amount of detail required and helpful?**		*Juliet Spiller (04-Jan-2018)* No just have exact wording in section 5 - "Does the person have sufficient capacity to participate in making the recommendation on this plan" Yes or No then presence or absence or (not known) of legal proxy *Paul Miller (04-Jan-2018)* Essentially yes but the Scottish legislation is different and arises from a different Act AFAIK, so the model below will not map to Scottish law. ***Editor Feedback*** @All: we'll rework this whole section> Suggestion is we simplify to just the two questions on the ReSPECT form + Peter-Marc's addition of 'Persons holding parental responsibility'
Date last updated Date/Time	The date that the record of power of attorney was last updated.		*Juliet Spiller (04-Jan-2018)* not needed
Mental capacity status Text	Patient's ability to make informed choices in terms of the Mental Capacity Act 2005.		*Juliet Spiller (04-Jan-2018)* no too confusing *Paul Miller (04-Jan-2018)* There are specific Adult with Incapacity forms and statuses I think as part of the 2000 Act which could be modelled. e.g Presence of an AWI form - currently on KIS but do not know what code it maps to.
Lasting power of attorney for personal welfare Cluster	Details of lasting power of attorney for Personal Welfare.		*Juliet Spiller (04-Jan-2018)* no too confusing
Power of attorney status	The status of any lasting power of	• Has appointed person with	*Ian Thompson (01-Jan-2018)* Where do we put stuff about

Coded Text	attorney.	personal welfare lasting power of attorney (Mental Capacity Act 2005) [The patient has appointed a person with personal welfare lasting power of attorney (Mental Capacity Act 2005).] • Has appointed person with personal welfare lasting power of attorney with authority for life sustaining decisions (Mental Capacity Act 2005) [The patient has appointed a person with personal welfare lasting power of attorney with authority for life sustaining decisions (Mental Capacity Act 2005).] • Lasting power of attorney personal welfare. [Paient has a lasting power of attorney for personal welfare.]	Adults with Incapacity Act (Scotland)/ these coded options are country (England) specific ! What about Wales @Annemarie?? *Juliet Spiller (04-Jan-2018)* too confusing as too many options depending on different country legislation *Paul Miller (04-Jan-2018)* http://www.publicguardian-scotland.gov.uk/power-of-attorney/power-of-attorney/types-of-power-of-attorney "Continuing PoA – gives powers to deal with money and/or property Continuing (financial) powers can be used by the attorney immediately after the PoA document has been registered with us. If the PoA is only to be used in the event of your incapacity, it must clearly state that the powers are not to be used until this happens. You may wish to add a statement about who should make this decision about your incapacity. Welfare PoA – gives powers to make decisions around health or personal welfare matters Welfare powers may only be acted upon after the PoA has been registered with us and when you have lost capacity to make decisions on matters to which the powers apply. Read the definition of incapacity. Combined PoA – gives continuing and welfare powers The majority of PoAs registered with us are a combination of continuing and welfare powers. However, it is your choice as to the type of PoA you wish to grant."
Person holding power of attorney Text	Details of the person holding power of attorney for personal welfare.		*Juliet Spiller (04-Jan-2018)* this goes in section 8
Lasting power of attorney for property and affairs Cluster	Details of lasting power of attorney for property and affairs.		*Catherine Baldock (03-Jan-2018)* Is this relevant to ReSPECT? *Juliet Spiller (04-Jan-2018)* no
Power of attorney status Coded Text	Status of lasting pwer of attorney for property and affairs.	• Lasting power of attorney property and affairs [The patient has appointed a lasting power of attorney for property and affairs.]	*Ian Thompson (01-Jan-2018)* Where do we put stuff about Adults with Incapacity Act (Scotland)/ these coded options are country (England) specific ! What about Wales @Annemarie?? *Catherine Baldock (03-Jan-2018)* Is this relevant to ReSPECT? *Juliet Spiller (04-Jan-2018)* no

Person holding power of attorney Text	Details of the person holding power of attorney for property and affairs.		*Catherine Baldock (03-Jan-2018)* Is this relevant to ReSPECT? *Juliet Spiller (04-Jan-2018)* no
Other person to be involved in decision-making Text	Details of any other person who the patient wishes to be involved in decision-making.		*Catherine Baldock (03-Jan-2018)* do we need this as same as box 6 below *Juliet Spiller (04-Jan-2018)* I really like this but it is not on the paper document so best leave out or now
6. Involvement in making plan Section	Details of those involved and discussions in making the ReSPECT plan.		
Involvement in recommendations Cluster	The clinician(s) signing this plan is/are confirming that these recommendations have at least one of A, B or C or valid reason for not selecting A,B or C fully documented in clinical record.		*Juliet Spiller (04-Jan-2018)* The clinician(s) signing this plan are confirming adherence to relevant capacity legislation and Human Rights legislation. At least one of A, B or C must be selected or a valid reason why not must be summarised in D and documented fully in the clinical record ***Editor Feedback*** @Juliet: we'll change the wording
Involvement Coded Text Mandatory	Details of involvement in recommendations.	• A Person has mental capacity [This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan.] • B Person does not have mental capacity [This person does not have the mental capacity to participate in making these recommendations. This plan has been made in accordance with capacity law, including, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.] • C1 Person less than 18 or 16 with sufficient maturity [This person is less than 18 (UK except Scotland) /	*Juliet Spiller (04-Jan-2018)* We need to flag up the requirement to explain in D if C1 or C2 has been selected without selecting C3 *Zoe Fritz (04-Jan-2018)* is it possible for C to be ' child' and then open up C1/2/3? we obviously could not do that on the paper form ***Editor Feedback*** @Juliet: we can add this to the description @Zoe: this would be done via guidance to app developers.

		16 (Scotland) and they have sufficient maturity and understanding to participate in making this plan.] • C2 Person less than 18 or 16 without sufficient maturity [This person is less than 18 (UK except Scotland) / 16 (Scotland) and they do not have sufficient maturity and understanding to participate in this plan. Their views, where known, have been taken into account.] • C3 Person less than 18 or 16 parental decision [This person is less than 18 (UK except Scotland) /16 (Scotland) and those holding parental responsibility have been fully involved in discussing and making this plan.] • D No other option selected [No other option has been selected, and valid reason is stated below. Full explanation is documented in clinical record.]	
Reason for not selecting Options A or B or C T Text	Description of reason for not selecting Options A, B or C.		*Juliet Spiller (04-Jan-2018)* or where C1 or C2 is selected without selecting C3 *Zoe Fritz (04-Jan-2018)* in an electronic format, if someone selects D we could have a line coming up explaining that the only legal reasons for selecting D are: 1. if the physician thinks it would cause the patient physiological or psychological harm 2. if the patient lacks capacity, and it is not practicable or appropriate to contact those close to them ***Editor Feedback*** @Juliet: we'll change the wording @Zoe: helpful comment which we'll include in guidance for app developer
Location of record of discussion T Text	Details of location of records of discussion about recommendations.		*Juliet Spiller (04-Jan-2018)* details of location(s) of full documentation of conversations and decision-making process

			We are missing the date, name and roles of those involved *Zoe Fritz (04-Jan-2018)* perhaps a prompt about where these might be e.g. in GP records dated x.x.x ***Editor Feedback*** @Juliet: we'll add these @Zoe: we'll add this as an example in the description
7. Clinician signatures Section	Details of clinicians involved in making ReSPECT plan.		
Relevant contact Admin Entry Optional, repeating	Relevant contact for the patient or client, including formal and informal carers, next of kin and key workers.		*Juliet Spiller (04-Jan-2018)* happy with editors comment but the text needs changed to reflect that ***Editor Feedback*** @Juliet: this will be added to implementation guidance.
Data			
Individual professional demographics (UK) Cluster Optional, repeating	Professional demographics details including name(s) , addresse(s) and telecommunication contact details.		
Person name Cluster	Details of personal name of an individual, provider or third party.		
Clinician name Text	Name in free text unstructured format.		
Specialty Text	The speciality of the carer.		*Peter-Marc Fortune (02-Jan-2018)* Should this be coded rather than free text? *Juliet Spiller (04-Jan-2018)* text is confusing - Health care professional rather than carer ***Editor Feedback*** @Peter-Marc: yes it could be coded, but speciality coding is somewhat challenging. @Juliet: we can change the wording, but we need to keep carer in there because the archetype itself has wider use.
Grade Text	The employment grade or position of the carer.		*Juliet Spiller (04-Jan-2018)* as above ***Editor Feedback*** @Juliet: see comment above
Professional Identifier Identifier	Professional identifier of the individual.		*Ian Thompson (01-Jan-2018)* Do we need to have both Prof ID and Prof ID type

			(GMC/NWC/AHPC/GDC) or is this *ALWAYS* going to completed by a doctor? ***Editor Feedback*** @Ian: underlying identifier data type supports this
Senior responsible clinician Admin Entry	Relevant contact for the patient or client, including formal and informal carers, next of kin and key workers.		*Juliet Spiller (04-Jan-2018)* again text needs amended to reflect what is in editors comment ***Editor Feedback*** @Juliet: see previous comment
Clinician name T Text	Name in free text unstructured format.		
Specialty T Text	The speciality of the carer.		*Juliet Spiller (04-Jan-2018)* HCP not carer ***Editor Feedback*** @Juliet: see previous comment
Grade T Text	The employment grade or position of the carer.		*Peter-Marc Fortune (02-Jan-2018)* This should definitely be coded as only small subset of professions: 1) Consultant 2) General Practioner 3) Specialist/Community Nurse *Juliet Spiller (04-Jan-2018)* as above ***Editor Feedback*** @Peter-Marc - we can do this, but group needs to agree the small subset @Juliet: see above comment
Professional Identifier ID Identifier	Professional identifier of the individual.		
Relationship category T Coded Text	The broad category of care relationship which the contact hods with the subject.	• Key formal care worker [The formal carer is the subject's key worker.] *Default value:* Key formal care worker	
8. Emergency contacts Section	Details of emergeny contacts for ReSPECT plan.		*Catherine Baldock (03-Jan-2018)* typo - emergeny should read emergency ***Editor Feedback*** @Catherine: we'll correct typo
Relevant contact Admin Entry Optional, repeating	Relevant contact for the patient or client, including formal and informal carers, next of kin and key workers.		
Name	Name in free text unstructured		

Text	format.		
Telephone Text	An unstructured description of telecom or other contact detials		*Peter-Marc Fortune (02-Jan-2018)* Facility for more than one form of contact would be useful. Should this be forced to confirm to a validated structure? *Paul Miller (04-Jan-2018)* Better to define a format though, as spaces and dashes and + can screw up e.g. SMS services ***Editor Feedback*** @Peter-Marc: we can have multiples. Structure is available in the underlying archetype, but experience shows it's almost impossible to enforce
Role Text	For an informal carer, the personal relationship with the client/carer e.g spouse or friend . For a formal carer, the professional role or responsibility of the carer with respect to the person which should help identify them as being an appropriate contact for an aspect of care, usually a professional role or care pathway name.	• Legal proxy or parent • Family or friend • GP • Lead consultant • Other	*Paul Miller (04-Jan-2018)* Probably need to split out Family / friend / Legal proxy / parent. Possible alos for people to have >1 role. ***Editor Feedback*** @Paul: these come directly from the ReSPECT form, it's a local subset so can be changed if required.
Other details Text	Any additional comment or note about the carer or their role.		
9. Confirmation of validity Section	Details of review dates and clinician for the confirmation of validity (e.g. for change of condition).		*Juliet Spiller (04-Jan-2018)* fine
Clinician name Text	Name in free text unstructured format.		
Specialty Text	The speciality of the carer.		*Peter-Marc Fortune (02-Jan-2018)* As above, coded *Juliet Spiller (04-Jan-2018)* HCP not carer as above
Grade Text	The employment grade or position of the carer.		*Peter-Marc Fortune (02-Jan-2018)* As above, coded not free text *Juliet Spiller (04-Jan-2018)* and again!
Professional Identifier Identifier	Professional identifier of the individual.		

Review date Date/Time	The date and/or time on which the service is intended to be performed. Comment: Only for use in association with the 'Service scheduled' pathway step.		

Overall Comments

Completeness and/or any missing elements	*Ian Thompson (01-Jan-2018)* Could benefit from optional structures to capture coded diagnostic elements in diagnosis sections. *Peter-Marc Fortune (02-Jan-2018)* This feels largely complete but would welcome discussion of how this interlinks with the archetypes (current or future) for elements referred to in these fields. *Juliet Spiller (04-Jan-2018)* only two things missing in section 6 which I have highlighted in comments at that point *Zoe Fritz (04-Jan-2018)* Thanks - very complete
General design issues of this archetype	*Ian Thompson (01-Jan-2018)* Generally OK, needs to consider legal regulations in all applicable territories when it comes to constrained lists of coded text. *Peter-Marc Fortune (02-Jan-2018)* Need to talk through each element and agree categorised entries where possible whilst continuing to permit free text when required. *Catherine Baldock (03-Jan-2018)* It appears very time consuming and lengthy to fill in all the information - will data be collected from other sources to pre-populate and will this be applicable in all care settings. How much data will be pre-populated? *Juliet Spiller (04-Jan-2018)* I am concerned that the amount of free text will make it challenging to complete and to read but I think it does reflect the essence of the form very well. Section 4 is the part I am least comfortable with but I would like to see it worked through with some live examples *Zoe Fritz (04-Jan-2018)* The section I struggles most with was the summary of relevant information, but maybe I have misunderstood it - I have written comments in that section. In summary, though, I think there should be 1. an option to select from known diagnoses 2. a narrative free text box where the clinician and patient can add relevant factors about the patients social and premorbid condition - e.g. lives at home with ads careers, can only walk 50 yards/ completely independent, continues to go to dance classes - i.e. the kind of thing that will not be ' coded' anywhere, but

	gives a good idea of the premorbid state of the patient, and where we might hope to get them to
Other resources	
Overall comments	*Peter-Marc Fortune (02-Jan-2018)* A great start - thanks! *Catherine Baldock (03-Jan-2018)* It is very comprehensive and contains some information which may not be immediately relevant to completion of the form and gathering this data may become a barrier to users if there is time pressure. The focus should be on the conversation with the patient rather than completing every data field *Juliet Spiller (04-Jan-2018)* I'm really impressed with this first draft - the challenge for future reviewers will be to comment on the archetype rather than agreed content of the form as visualising electronic completion throws up so of the issues we have grappled with and "resolved" over the past few years so reviewers coming new to the ReSPECT process may struggle with this aspect. *Zoe Fritz (04-Jan-2018)* Thank you - look forward to discussing further!
Overall recommendation	*Ian Thompson (01-Jan-2018)* Minor Revision *Peter-Marc Fortune (02-Jan-2018)* Major Revision *Catherine Baldock (03-Jan-2018)* Minor Revision *Juliet Spiller (04-Jan-2018)* Minor Revision *Zoe Fritz (04-Jan-2018)* Major Revision *Paul Miller (04-Jan-2018)* Major Revision