TITLE Centralisation of specialist health care services: a mixed-methods programme

SHORT TITLE CENT

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STUDY SUMMARY

Full Title:	CENT: Centralisation of specialist health care services: a mixed-methods programme
Health condition(s) or problem(s) studied	Centralisation of specialist health care services
Study type	Mixed methods study comprising a scoping study, a discrete choice experiment, and qualitative research to develop a taxonomy to classify different models of centralising specialist health care services in the UK, for use by commissioners and other evidence users when deciding whether and how to centralise these services. Note that this protocol is the core of a wider proposed programme of research, which will include one or more empirical studies to evaluate the impact of centralising specialist health care services in specific clinical domains.
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KEY WORDS

Centralisation

Specialist health care services

Mixed methods

Scoping review

Survey

Discrete choice experiment

Taxonomy

Quality improvement

Stakeholder preferences

Service models

LIST OF ABBREVIATIONS

DCE – Discrete Choice Experiment

DSH – Data Safe Haven

FTP - File Transfer Protocol

GDPR - General Data Protection Regulation

IP - Intellectual Property

MRS - Marginal Rates of Substitution

NHS – National Health System

NICE – National Institute for Health and Care Excellence

NIHR - National Institute for Health Research

PPI – Patient and Public Involvement

PIS – participant information sheet

RAP - Research Advisory Panel

SCOG - Specialised Commissioning Oversight Group

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1. INTRODUCTION

1.1 Brief Overview

There have been significant changes in the provision of specialist clinical care in the NHS in recent years, with plans to centralise specialist services into fewer centres. Specialist services are not available in every hospital because specialist teams of health care professionals with the required knowledge, skills and experience usually deliver them. There have been longstanding recommendations for centralisation of specialist services. [1, 2] The aims of this study are to use quantitative and qualitative research methods to investigate (a) how the centralisation of specialist health care services in the UK can be characterised, (b) how different approaches/models to centralisation might work better in different settings, and (c) whether and how patients, general population, health care professionals, hospital managers and commissioners would prefer specialist health care services to be centralised.

The objectives are:

O1. To undertake a novel scoping review to identify what "centralisation" as a service innovation means in the context of specialist health care services, and what the dimensions of centralisation are.

O2. To use the scoping review to develop a taxonomy to map the different models of centralisation.

O3. To identify in conjunction with the funder and NHSE&I specific conditions of interest for centralisation of specialist health care services in England and conduct original discrete choice experiments (DCEs) to analyse the preferences of patients, general population, health care professionals, hospital managers and commissioners.

These objectives represent new research that, to the best of our knowledge, has not been undertaken previously.

The associated research questions are:

RQ1: What are the general features and dimensions of 'centralisation' of specialist health care services as a service innovation?

RQ2: How might centralisations of specialist health care services be classified?

RQ3: What are the preferences of patients, general population, health care professionals, hospital managers and commissioners for centralised specialist health care services?

Note that this protocol is the core of a wider proposed programme of research, which will include one or more empirical studies to evaluate the impact of centralising specialist health care services in specific clinical domains. These evaluations will overlap the current study and could include evidence reviews of the effectiveness and cost-effectiveness of

centralisation, impact evaluations on patient outcomes, processes of care, and costs and cost-effectiveness, evaluations of stakeholder preferences, implementation studies.

To meet these objectives we will use mixed research methods, including quantitative analysis methods to evaluate the impact of centralisation on outcomes and processes of care, economic analysis methods to evaluate value for money, and qualitative methods to understand implementation. The results of the scoping review will help in identifying which service(s) to study, but in general they will relate to the service or settings that are poorly studied or centralisation of services that will be initiated in the near future. Key factors in deciding which service to evaluate are when the centralisations occurred/will occur and timely access to data to evaluate them. A separate protocol and research ethics application will be produced for each evaluation.

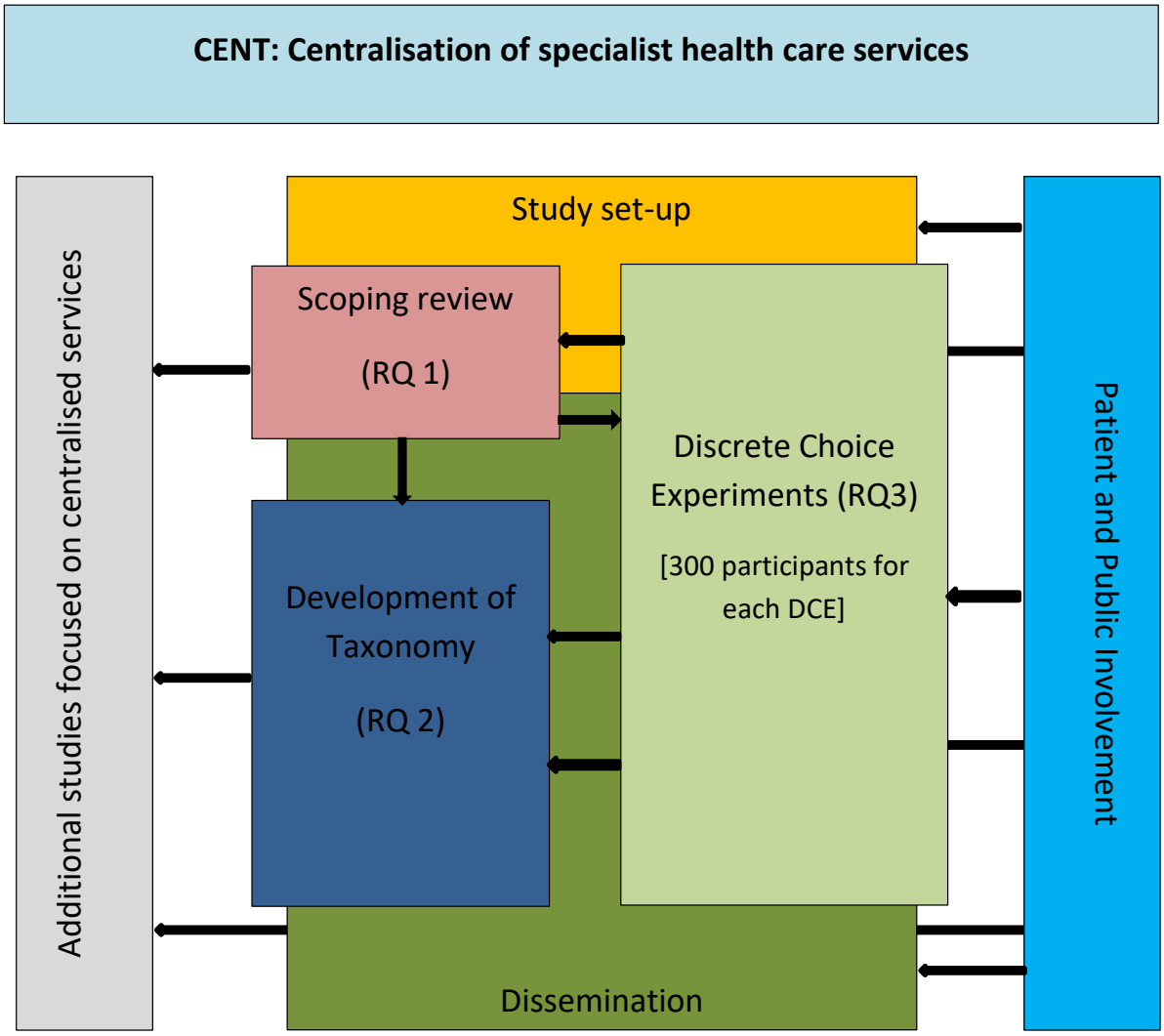
1.2 Summary of methods used

For RQ1 we will undertake a scoping review to identify the key components of centralisation for specialist health care services in the context of service innovation. This scoping review will map the diverse body of published and grey literature that exists around the main features of centralisation for specialised services. For RQ2 we will use the scoping review to develop a taxonomy of different models of centralisation. Using the findings of the scoping review plus other most specific reviews, for RQ3 we will conduct discrete choice experiments to elicit preferences for centralisation of selected specialist health care services of key stakeholder groups.

1.3 Main benefits of the research

The proposed research will be developed in partnership with research users, to maximise its usefulness and impact. It will provide new data for research users on what patients, general population, health care professionals, hospital managers and commissioners think about the centralisation of specialist services, which issues matter to them the most when considering this, how strongly they feel about these issues, and their preferences with regard to the centralisation of specialised services. We will discuss the key components of centralisation of specialist health care services by developing a taxonomy that could be used by other research teams exploring centralisation in other healthcare contexts/specialties. Results of this research will inform policy makers and other research users on how the centralisation of specialist services might be best organised around the needs and preferences of main stakeholders.

1.4 Study Flow Chart



2. BACKGROUND INFORMATION

Studies from several countries have suggested that centralising specialist health care services into fewer consolidated units can improve provision of evidence-based care processes by increasing access to specialists, reaping better outcomes associated with higher volumes, and reducing hospital stay. [3-27] The rationale is that centralisation leads to increased volumes of cases at specialist centres, meaning that more patients have access to specialist staff expertise, resource availability and specific processes of care correlated with volume. [28, 29] In addition, treating more cases can lead to greater experience and expertise in dealing with patients. Under centralised systems specialist services may also be able to enhance access to innovative techniques and technologies, including less invasive procedures. [30, 31]

On the downside, for many patients and families centralisation affects distance to hospital and travel time. Some studies have indicated that patients may be, to some extent, willing to travel further and longer to receive specialist care in return for clinical benefits, however, research evidence indicates that distance and travel time are largely seen as limiting factors in patients' decisions to access treatment, especially for patients living in socio-economically

deprived areas. [32-41]. Increased opportunity costs and direct out-of-pocket payments associated with travel are also more likely to affect less well-off families, which may also be in the greatest need. [42] Moreover, increased journey distances increase travelling times that may lead to increased risks in patients with life-threatening medical emergencies. [43]

Some research has suggested that, with centralisation, patients who do not reach a specialised centre experience significantly worse care in the other services. [44]

While, as discussed above, there are several studies examining the impact of centralisation of health services on patients' outcomes, there has been little research to understand the main characteristics of centralisation, including no previous reviews. In addition, there are many different ways in which services may be centralised, and different approaches/models to centralisation might work better in different settings (such as rural versus urban settings). A comprehensive taxonomy that maps the underlying dimensions of centralisation, and describes the circumstances under which different models would work best, is currently lacking. The development of such a taxonomy would help in pinpointing the focus of future investigations and would also allow exploring centralisation in other healthcare contexts and specialities. Additionally, there are only a few studies that look at stakeholders' preferences for centralising health care, and such studies tend to focus on particular services or aspects of services while there is a clear need for the understanding of how centralisation works in different settings. Priorities and preferences of different stakeholder may be quite different depending on the care context and therefore there is a need to understand such priorities and preferences especially when it comes to different settings. [45]

3. AIMS AND OBJECTIVES

3.1. Aims

The aims of this study are to use quantitative and qualitative research methods to investigate (a) how the centralisation of specialist health care services in the UK can be characterised, (b) how different approaches/models to centralisation might work better in different settings, and (c) whether and how patients, general population, health care professionals, hospital managers and commissioners would prefer them to be centralised.

3.2. Objectives

1. To undertake a novel scoping review to (i) identify what "centralisation" as a service innovation means in the context of specialist health care services, and (ii) identify what the dimensions of centralisation are.

2. To develop a taxonomy to map the different models of centralisation.

3. To identify in conjunction with the funder and NHSE&I specific conditions of interest for centralisation of specialist health care in England and conduct original discrete choice experiments (DCEs) to analyse preferences for centralisation of specialist health care services by patients, general population, health care professionals, hospital managers and commissioners.

These objectives represent new research that, to the best of our knowledge, has not been undertaken previously.

3.3. Additional studies focused on specific centralised services

This protocol is the core of a wider proposed programme of research, which will include one or more empirical studies to evaluate the impact of centralising specialist health care services in specific clinical domains. Potential areas are the centralisation of acute stroke services to enable provision of thrombectomy services, vascular surgery services, and/or children's and young people's cancer services. The services to be evaluated will be discussed/agreed with the funder and with NHSE&I. These evaluations will overlap the current study and will include one or more of the following objectives:

- To undertake evidence reviews of the effectiveness and cost-effectiveness of centralisation in these specific contexts.
- To evaluate the impact of the specific centralisation on patient outcomes, processes of care, and costs and cost-effectiveness.
- To evaluate stakeholder preferences for the specific centralisation, e.g., using discrete choice experiments.
- To evaluate the implementation of the specific centralisation, identify lessons learned, and combine these with lessons from previous studies.

To meet these objectives we will use mixed research methods, including quantitative analysis methods to evaluate the impact of centralisation on outcomes and processes of care, economic analysis methods to evaluate value for money, and qualitative methods to understand implementation. The results of the scoping review will help in identifying which service(s) to study, but in general they will relate to the service or settings that are poorly studied or centralisation of services that will be initiated in the near future. Key factors in deciding which service to evaluate are when the centralisations occurred/will occur and timely access to data to evaluate them. A separate protocol and research ethics application will be produced for each evaluation.

4. STUDY DESIGN

4.1. Overall design of the study

This is a mixed-methods study that will combine qualitative and quantitative approaches to analyse the centralisation of specialist health care services and the preferences for this reorganisation among different groups like, patients and carers, general population, health care professionals, hospitals managers and commissioners. The components of the study designed to answer the research questions are as follows:

Scoping review (RQ1): This review will identify the general features and components of 'centralisation' of specialist health care services as a service innovation. The review will

focus on the available literature about centralisation of specialist health care services to identify and map different dimensions of centralisation.

Taxonomy (RQ2): The scoping review will be used to develop a taxonomy of different models of centralisation, including how these different models might work better in different settings.

Discrete Choice Experiment (RQ3): We will conduct a number of condition specific DCEs to examine preferences for centralised specialist of health care services, relative importance of attributes of centralised care, and how preferences vary between stakeholders. The questionnaire and DCE design will be informed by the scoping review. The questionnaire will be piloted before implementation.

4.2. Study setting/context

This study is concerned with the reorganisation of specialised care in the UK. Our primary focus is NHS care. The study will include a range of geographical settings, as we are interested in understanding variation in the type of service model, which may vary by geographical area, depending on access to specialised centres. Limits will also be set according to what is considered specialised care services in the UK (i.e., care services typically provided to patients with complex conditions requiring cutting-edge investigations or other treatments of a specialist nature, but excluding reconfiguration of emergency services or maternity services, which are typically not viewed as specialist services given their availability to large sections of the population), as we wish to identify only experiences and preferences regarding these particular services.

Given this setting, there are several stakeholder groups who will be involved in the study including:

- Patients and families, including parents and carers of children under 18 years of age requiring specialised care;
- Patient organisations, charities and other third sector organisations;
- Clinical experts from specialised care (caring for both adults and children);
- NHS commissioners in the UK;
- NHS providers across primary, secondary and tertiary care at service and governance levels; and
- Policy-makers (e.g., the Specialised Commissioning Oversight Group (SCOG) at NHSE).

4.3. Scoping review (RQ1)

4.3.1. Objectives

The objectives are to identify what characterises “centralisation of specialist health care services” as a service innovation. This will include producing a formal definition of what centralisation means in this context, what the components of centralising specialist care are, and the advantages and disadvantages of different models of centralisation in different settings.

Unlike systematic reviews and meta-analyses, scoping studies "aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as standalone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before."[69] In this study we will examine the extent, range and nature of research on centralising specialist health care services and will follow the five stages of the methodological framework for conducting scoping studies. [46-48] This will build on the team's experience of conducting rapid scoping reviews. [49, 50] We will use the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for scoping reviews (PRISMA-SCr) statement to guide the reporting of the methods and findings. [52]

4.3.2. Stage 1: Identifying the research question:

The scoping review will aim to provide a rapid mapping of the literature on centralisation of specialist health services (i.e. reorganisation of specialised healthcare services that is characterised by fewer specialised units serving a higher volume of patients), including the main domains/dimensions of centralisation, the settings where it is applied, and the advantages and disadvantages of different models of centralisation in different settings. Specific questions that the scoping review will address are the following: what does "centralising specialist health care services" mean? What are the elements of centralising specialist services? How do the different models of centralisation work in different settings?

4.3.3. Stage 2: Identifying relevant studies

We will conduct a review of the existing evidence on different aspects of centralising specialist care in general (considering all service settings and not limited by disease, condition or type of treatment or investigation provided). This will aim to identify the main factors involved in centralisation of the specialist care.

We will adopt a phased search strategy approach, where we start from broad terms and narrow it down to ones that are more specific. Articles published in peer-reviewed journals, as well as grey literature such as commentaries and think-tank reports will be included and used to develop a theoretical understanding of the main characteristics of decentralisation. We will not be limiting the review by research design including previous literature reviews, quantitative and qualitative studies as well as the grey literature. The searching for evidence will comprise a range of different sources, as follows:

- Electronic databases (e.g., MEDLINE, Scopus, CINAHL Plus, Web of Science, ProQuest Social Science, and ProQuest Nursing and Allied Health);
- Grey literature sources such as Health Management Information Centre, Open Grey and TRIP medical databases, including proposals for centralisations;
- Other researchers working in this area; and,
- Reference lists of retrieved studies.

We will not limit the search to a certain period of time, to capture relevant major policy changes. Unless stakeholders are aware of important papers in languages other than English, foreign language material will be excluded because of the cost and time involved in translating material.

4.3.4. Stage 3: Literature selection

Selection criteria for identifying relevant literature will be developed iteratively, based on increasing familiarity with the literature, including a clear description of the characteristics of the centralised model being implemented. Following the review methodology outlined by Tricco et al (2017), an experienced researcher will screen the articles in the title phase, while a second reviewer will cross-check a random sample of exclusions. Disagreements will be discussed until consensus is reached. We will acknowledge the potential limitations of this approach in the review paper.

4.3.5. Stage 4: Charting the data

We will extract data obtained from the selected research reviews, quantitative and qualitative studies as well as the grey literature included in our scoping review. For each study we will record and then code the following in order to contextualise the domains covered by each of the selected studies:

- What type of service was being centralised (e.g., emergency or elective, type of treatment or investigation);
- The rationale for centralisation.
- How services changed with the centralisation/the centralisation model (e.g., number of centres before and after centralisation, how the services interacted with one another);
- The health condition(s) relevant to the centralisation;
- The setting of the centralisation (e.g., rural or urban, population size/geographical affected);
- How the centralisation was implemented (e.g., consultation process, decision-making processes);
- Over what time period the centralisation was implemented; and
- The evidence that was used to inform the centralisation.

A data extraction form will be used for data extraction. REDCap (Research Electronic Data Capture) will be used to extract the data and it will be exported in the form of a spreadsheet. It will then be piloted independently by two researchers using a random sample of five articles. Disagreements will be discussed until consensus is reached. The data extraction form will be finalised based on the findings from the pilot. REDCap is able to provide a summary of extracted quantitative data and we will synthesize the qualitative data using framework analysis.

Our extracted data will include the rationale for centralisation. We do not know if the data will be enough to build the taxonomy, but if this is not possible the data will be used to answer the other research questions outlined for the scoping review.

Our aim of developing mid-range theories will be based on our attempt to explore the different models of centralisation and identify their main characteristics.

Patients and members of the public will be consulted during the design of the review and when emerging findings have been obtained as part of the stakeholder consultation processes outlined by Arksey and O-Malley (2005) for scoping reviews.

4.3.6. Stage 5: Collating, summarising and reporting the results.

We will present an overview of all materials reviewed. This will include tables mapping the characteristics of the included studies, and thematic analysis of their results.

We will also use the information generated by the scoping review, and the subsequent taxonomy (see below), to inform the development the DCE in RQ3, plus to inform the selection of the additional studies focused on specific centralised services described in section 3.3.

4.4. Taxonomy (RQ2)

The mapping process from stage 5 of the scoping review will also be used to develop a taxonomy of the different models of centralisation, including how these different models might work better in different settings. A taxonomy is a system for classifying multifaceted, complex phenomena according to common conceptual domains and dimensions. The aim is to distil complex interventions into their essential components, thereby allowing the comparison of alternative service models. To derive the taxonomy, we will utilise the finalised code structure described above for charting the data, with the structure of the taxonomy mirroring closely the conceptual codes and their sub-codes, defining key domains that characterise the centralisation of specialist health services.

The main outputs from this research will be a series of mid-range theories [52] (theories that are sufficiently abstract to be generalised, while still sufficiently grounded in evidence to be tested in practice) of what “centralising specialist health care services” means.

4.5. Discrete Choice Experiment (RQ3)

4.5.1. Objectives

The objective of the DCE is to analyse preferences of patients, general population, health care professionals, hospital managers and commissioners for centralised specialist health care services in one or more care settings. This will provide new data on what these stakeholders think about centralising specialist services, which issues matter to them the most when considering this, and which factors they prioritise most strongly. Responders will be asked to reveal their preferences on centralisation for a specific condition for which specialised care is expected to go (or is going or has already gone) through this reorganisation.

The specific conditions on which the selection of the DCE(s) will be based will be identified through the scoping review. Selection of health conditions for the DCEs will be based on factors to be determined during the scoping review. One factor guiding this choice is likely to be the phase of the centralisation restructuring (with a preference for conditions where centralisation is happening or where centralisation has been set as a priority by decision-makers). Another factor is likely to be the gaps in knowledge identified in our scoping work (e.g. if there is little evidence on centralising specialist services for a particular condition that is planned or underway, or centralisations carried out in some particular geographic

settings). Researchers will discuss the set of factors during the scoping review and will take a decision on the conditions to select. The attributes included in the DCE (see below) will be informed by the work to develop the taxonomy, the timeframe for which will overlap partly with the DCE.

4.5.2. Questionnaire development

Once the conditions have been selected, the DCE will be designed to elicit preferences for the way in which care is centralised for all groups of respondents. The process for designing the DCE questionnaire will be as follows:

a. After identifying the specific conditions to focus on from the scoping review and consultations with stakeholders we will undertake 5-10 semi-structured qualitative interviews per service with key stakeholders (patients and health care professionals, including hospital managers and commissioners) to identify the important attributes associated with centralisation of the specialist service. Interviewees will also be asked about their experiences of different models of centralisation of the specialist service to inform the taxonomy (RQ2). We will conduct the interviews by telephone or Skype. Interviews will be audio-recorded, transcribed and analysed thematically. An initial list of factors that might be affected by centralisation of each service will then be compiled based on the above interview findings plus the research evidence from the scoping review.
b. A long list of attributes will be drawn from the above by the research team. This long list will describe the characteristic and potential outcomes of centralising specialist services and could potentially include: health outcomes; processes of care; travel distances; travel costs; out-of-pocket expenses incurred when receiving care; links between specialist and local providers; health care professionals' workload; the collaboration with the other health professionals who have the necessary skills and experience. Based on previous studies we have run, the DCE will include a maximum of seven attributes, as having more attributes than this can make the DCE difficult for participants to understand and complete. Attributes will be selected so that there is minimal overlap between them; any residual overlap will be accounted for in the multivariate regression analyses (see below).
c. A preferred list of up to seven shortlisted attributes to be included in the DCE will be informed by re-contacting the stakeholders included in the original interviews described above and asking them to rank the long list, thereby producing a short list of selected attributes. This preferred list of attributes will also be reviewed by the research team.
d. We will assign levels to these attributes based on feasible ranges derived from the scoping review and the interviews.
e. We will design each of the condition-specific DCEs questionnaire using a pairwise choice framework and will compile a set of pairwise scenarios that describe the feasible combinations of levels and attributes of different models of centralise health service. Respondents will complete 8-12 choice questions. Using a pairwise choice framework, in each choice question respondents will be asked to choose one of two models of care presented to them which are differentiated by their attributes. We

will include an opt-out option within the pairwise choice framework, allowing respondents to pick neither of the offered choices. The experimental design will include main effects only. The number of pairwise choices will be reduced to a manageable number for participants to answer based on a fractional design applied using the –dcreate– command in Stata, [53] which creates efficient designs for DCEs. Based on previous evidence and our own experience about the maximum number of choice questions respondents are able to answer, we will keep the total number of feasible pairwise choice questions to a maximum of 12.

f. As part of the questionnaire we will also ask respondents to providing a simple ranking of the attributes according to importance.

The questionnaire will then be piloted with 6-10 respondents (2-3 think-aloud interviews, 4-8 providing written feedback) and amended according to the feedback received.

4.5.3. Sampling

For each of the condition-specific DCEs the three main participant groups will be: (i) patients suffering from the particular condition (ii), members of the general population, and (iii) health care-related professionals, including clinicians, managers and commissioners. We have a minimum target of 300 responses over all groups (i.e., 100 patients, 100 members of the general public and 100 health care-related professionals). The DCE questionnaire will be completed electronically, online via a dedicated website (see below).

The appropriate sample size for the DCE depends on the question format, the complexity of the choice tasks in terms of number of choice sets and alternatives in each choice sets, the desired precision of the results, the assumption of heterogeneity in the study population, the availability of respondents and the need to conduct subgroup analysis. [88] Louviere et al. (2000) provide a formula to define the minimum sample size, which is determined by some desired level of accuracy of the choice probability (or proportion be more important in the study. [89] Based on previous studies a sample size of 300 is commonly recommended. [54-57] Such minimum value across our three main groups gives us confidence that analyses undertaken separately on these groups will be adequately powered. In the general population sub-group, we aim to obtain an equal sample of respondents from residents in urban areas and in rural areas.

For both the preparatory interviews and the main DCEs the inclusion and exclusion criteria will be as follows. The general population group will comprise adults aged 18 years and over. Professionals will comprise doctors, nurses and allied health professionals involved in the care of people. We will also include national leads on specialist healthcare commissioning, as well as local commissioners of services. People aged under 18 years will not be included in the study. We will make provision for potential participants who are not able to understand English to be included in the study, e.g., by translating the DCE questionnaires. This provision will be discussed/agreed with the funder. We will note these as limitations in study publications.

4.5.4. Recruitment and consent

For the preparatory interviews involving patients the recruitment and consent process will be as follows. First, the activity will be advertised via patient charities and associations with clearly defined eligibility criteria. Interested individuals will be invited to approach the study researcher by email or 'phone and will be asked to provide information about themselves with respect to the eligibility criteria. If these criteria are met the study researcher will contact the potential participant and explain the purpose of the study verbally by 'phone, and provide a participant information sheet. If the potential participant is still interested and agreeable, the researcher allows at least 48 hours to elapse, then contacts the potential participant again to ask for his/her agreement to participate in the activity. The potential participant will be free to withdraw at any point: when first approached, again when asked for agreement 48 hours later, and at any point subsequently, up to and during the actual interview and may request for their data to be withdrawn after it has been collected prior to its anonymised publication. A consent form is completed prior to the interview; written consent will be obtained for face to face interviews; consent will be obtained via posted hardcopies or via email for phone or Skype interviews.

For interviews with health professionals the same process will be followed. In addition, potential professional participants may be approached initially by the study researchers via email or phone. Participants who are unable to provide consent will not be included in the study.

For the main survey and DCE the recruitment and consent process for all participants will be different. The final approved version of the online questionnaire will include a cover letter and participant information sheet (PIS) embedded at the start of the questionnaire informing potential participants about the study, what participating will entail, how data will be managed and stored, and who they can contact if they have questions or encounter any issues. For patients, participants will be recruited via patient organisations and charities. Initially this will be via email including a weblink to the online survey and the embedded PIS; patient organisations may then choose to pass on this information to their members by other means. The weblink to the online survey and associated information will also be distributed widely via social media channels (including Facebook and Twitter). For the general public we will recruit participants by advertising the DCE through health-related charities' websites, newsletters, and email list services and social media. The advertisements will include a link to the online questionnaire and associated study information, plus details of how to access it via email. Health professionals will be reached through the relevant professional organisations including Royal Colleges, Clinical Research Networks and Applied Research Collaborations. We will advertise the study through these organisations' websites, newsletters, and email list services. The advertisements will include a link to the online questionnaire and associated study information, plus details of how to access it via email.

In terms of recruitment and consent documentation, participant information sheets will be developed by the research team with PPI input from the RSET PPI group. Every PIS will clearly describe the purpose of the study activity, how long undertaking the activity is

estimated to last, and state that any (personal or research) data will be stored securely and not used for any purpose beyond this analysis. They will also state that participation is entirely voluntary, that participants may withdraw at any time, and who they should contact if they have questions or encounter any issues. For the survey and DCE the materials will additionally state that completion of the survey implies consent to participate. For the online questionnaire, an opening page will provide equivalent information and consent details plus a link to the data policy on the study webpage; to begin the survey, participants will have to press a button stating "I understand - click here to take the survey", which equates to giving consent to participate.

4.5.5. Questionnaire production

The questionnaire will be processed through a free and open source survey software, LimeSurvey, and made available on-line via a dedicated website. Respondents will complete the questionnaire electronically, upon receiving an emailed invitation to do so. The email will include a weblink to the online questionnaire.

4.5.6. Data analysis

We will estimate the preferences for centralised specialist services and the weighting of the relative value attached to attributes determining these preferences. The analysis will also provide an indication of respondents' willingness to trade between attributes. We will analyse preference data using either conditional logit or mixed logit regression analysis, as recommended in international guidelines. [54] The results will indicate which attributes significantly affect preferences, and which attributes are most and least important to respondents, conditional on the other attributes included in the analysis. Data will be analysed for all respondents jointly and separately for the participant sub-groups. We will deal with sample heterogeneity using covariate adjustment in regression analyses. We will analyse preferences by geographical location of the respondent (urban or rural). We will use the findings to calculate marginal rates of substitution (MRS) with respect to costs. The MRS allows direct assessment of how much of one attribute participants are willing to trade for one unit of another attribute and therefore enables a comparison of different attributes on a common scale. To calculate the MRS involves dividing the coefficient for each attribute by the coefficient for the 'cost attribute'. Calculating MRS values using the cost attribute as the denominator, gives a measure of the 'willingness to pay' for each attribute, e.g., providing a measure of how much respondents are on average willing to pay for a centralised specialist service. We will also use the regression results to calculate the predicted probability that different combinations of the attribute levels (i.e., different models of care centralisation) would be selected. This will allow us to rank different models of centralisation of specialist service in terms of their order of preference by the participants, [56, 57] and to explore how this ranking varies by group. The relative importance of each attribute will be calculated as the difference in preference weights between the best or most preferred level of each attribute and the worst or least preferred level of the same attribute. [58]

The ranking exercise included at the end of the DCE will also be used to show the relative importance of the different attributes; this is an imperfect measure as it does not account for the attribute levels. We will ask respondents to rank the attributes included in the DCE in

order of importance to them. We will present the results graphically as 100% stacked bar charts showing the proportion of respondents who ranked each attribute first, second, third, fourth, etc. We will present these data for all respondents combined and also for the sub-groups. We will measure inter-rater agreement using kappa statistics. We will put this after the DCE in the questionnaire so it does not influence the DCE responses (e.g., by encouraging non-trading).

5. ETHICAL ISSUES

5.1. Assessment and management of risk

The study may raise potential issues for our anticipated participant groups. For all participants, DCEs by design ask people to make hard choices between things that matter to them, which can be stressful. For patients and the general population, participation in study activities may potentially cause distress when considering potential experiences of care with and without centralisation. For professionals, it is possible that the situations presented might cause distress in terms of raising personal concerns in relation to potential changes to their own services, or in terms of their own concerns in relation to quality of care associated with centralisation. To address these concerns, the research team will review the DCE survey tools and interview topic guides to ensure that the questions and topics to be discussed are presented in a sensitive fashion. In addition, the Participant Information Sheets will make clear the (minimised) risk of distress, and make clear that participation is voluntary, and that participants may withdraw at any stage.

In addition, patients, the general population and professionals engaged in commissioning, planning and/or delivering services may feel reluctant to raise criticisms of services provided in any of the above research activities, which may affect the validity of the DCE and the interviews. The Participant Information Sheets will make clear the independence of the researchers involved in these activities, the importance of identifying challenges as well as successes, and that findings from the interviews and questionnaires will be anonymised.

The DCE will be completely anonymised. Participants will be informed in the PIS about the limits of confidentiality when participating in the interview component of the study. While the researchers may use quotes from participants in written reports, academic publications or conferences, participant's real names will not be used, and every effort will be made to protect the identity of participants. However, we will make it clear that it will not be possible to completely guarantee that an individual could not work out the identity of a participant. For that reason, participants will be given the opportunity to opt in or out of being quoted on a consent form.

5.2. Ethical approval

NHS Research Ethics Committee approval will be obtained for the interviews, piloting and DCE survey, undertaken to address RQ3.

6. PATIENT AND PUBLIC INVOLVEMENT (PPI)

Patients and the public will be actively involved in the study in the following ways:

- Patient representatives from a local Research Advisory Panel (RAP), comprising patient representatives and members of the public, provided feedback on the protocol and will provide ongoing review and feedback throughout the study (including dissemination).
- Patients and public, including patient groups and the voluntary sector, will also be involved extensively in the additional case studies described in section 3.3.

Recommendations on effective involvement and payment of patients and members of the public will be followed. [59-62]

7.DATA HANDLING AND MANAGEMENT

7.1. Data transfer (handling, processing and storage)

7.1.1. Qualitative data (interviews) for DCE design

Interview data to assist with the design of the DCEs will be collected from participants in accordance with the consent forms and participant information sheets. Interviews will be recorded on an encrypted, password-protected digital audio recorder to which only the researcher knows the password. Data collected by the qualitative researchers will be anonymised and transferred into the UCL Data Safe Haven (DSH) where it will be stored securely for analysis. The data will be cleared from the digital audio recording device when it has been transferred. Participant identifier codes will also be stored in the DSH and will be kept completely separate from study data. Interview data will be anonymised and organised by participant codes.

Digital audio recordings of interviews will be appropriately sent by secure File Transfer Protocol (FTP) transfer to for a professional transcription company for transcription. Digital audio recordings of interviews and anonymised interview transcripts will be stored for analysis on a secure computer network to which only named team members have access via password-protected computers at the UCL Department of Applied Health Research. Only the research team will have access to interview participants' personal data (i.e. name and status). Any paper-based data – such as signed written consent forms – will be stored in locked filing cabinets in security card protected office space at the UCL Department of Applied Health Research.

SM will act as the data controller of such data for the study. He will process, store and dispose of all qualitative data in accordance with all applicable legal and regulatory requirements, including the General Data Protection Regulation (GDPR) and the new UK Data Protection Act 2018 and any amendments thereto. Data will not be transferred to any party not identified in this protocol and are not to be processed and/or transferred other than in accordance with the patients' consent.

7.1.2. Quantitative data (DCE survey)

Electronic data collected as part of the DCE survey will be transferred securely using the Data Transfer Portal into the UCL Data Safe Haven (DSH; https://www.ucl.ac.uk/isd/itforslms/services/handling-sens-data/tech-soln). All electronic data will be stored, handled and analysed within the DSH. This is a secure electronic

environment that has been certified to the ISO27001 information security standard and conforms to the NHS Information Governance Toolkit. It has a file transfer mechanism that enables information to be transferred securely.

No data will be stored or transferred outside of the EU.

SM will act as the data controller of quantitative data for the study. He will process, store and dispose of all quantitative data in accordance with all applicable legal and regulatory requirements, including the General Data Protection Regulation (GDPR) and the new UK Data Protection Act 2018 and any amendments thereto. Data will not be transferred to any party not identified in this protocol and are not to be processed and/or transferred other than in accordance with the participants' consent.

8. TIMELINES

Date	Activity
02/2021	**RQ1. Scoping review** to identify what "centralisation" means in the context of specialist health care services, and what the components of centralisation are
08/2020	Identify review questions
10/2020	Identify relevant studies
11/2020	Select studies
12/2020	Chart the data
02/2021	Collate, summarise and report the results
03/2021	Write paper
02/21	**RQ2. Taxonomy** of different models describing how specialist health care services could be centralised
01/2021	Charting data for taxonomy development
02/2021	Finalise taxonomy
04/2021	Write paper
09/21	**RQ3. Discrete choice experiment** to analyse preferences for different models of centralisation of specialist health care services
02/2021	Ethical approval
02/2021	Identify attributes and levels for DCE
03/2020	In-depth interviews
04/2021	Create questionnaire
05/2021	Pilot questionnaire
08/2021	Survey distribution and collection
09/2021	Data analysis
10/2021	Write paper
10/2021	**Final report** to funder

9. MONITORING AND AUDITING

SM will ensure there are adequate quality and number of monitoring activities conducted by the study team. This will include adherence to the protocol, procedures for consenting and

ensure adequate data quality. They will inform the sponsor should he/she have concerns which have arisen from monitoring activities, and/or if there are problems with oversight/monitoring procedures.

The research team will meet approximately monthly throughout the study to discuss the status of the project, support progress with data collection and analysis, and to ensure effective dissemination of findings and stakeholder engagement. These meetings will be chaired by SM; administration will be provided by the project manager; teleconference and videoconference facilities will be used to optimise participation from research team members based outside of UCL.

Sub-groups of the research team will be formed to lead on particular aspects of data collection and analysis. The subgroups will report on progress to the whole project team at the research team meetings. At these meetings findings from each sub-group will be discussed and interdependencies and mutual learning between each element of the project will be explored.

Project oversight will be provided by the rest of the RSET and the RSET Stakeholder Advisory Board.

10. INTELLECTUAL PROPERTY

While the researchers possess substantial know-how relating to this research study, they do not hold intellectual property (IP) in this area.

This research may generate new IP. Any such product will be dealt with appropriately with guidance from UCL Business (see below), and in partnership with the other parties involved in the study.

During the project we anticipate producing the following IP:

1. The taxonomy of different models describing how centralisation of the specials care may be coordinated (RQ2).
2. Survey tools for evaluating the preferences of stakeholders (RQ3).
3. Dissemination materials produced throughout the study.

These will be protected by copyright law, according to the Copyright, Designs and Patent Act 1988. Copyright law protects any work which is written and is original. We will use “(c) University College London” (followed by the year of creation) to make clear that UCL asserts its right to copyright protection in these works.

IP generated through this research will be managed by UCL Business, who will work closely with the project team to ensure that any valuable IP is protected by patent filing or copyright as outlined above. Our dissemination plan allows for free and open access publication of the intervention manuals and peer-reviewed journal articles. Should the interventions prove effective and cost effective we anticipate they will be adopted by NHS commissioners across the UK as new models for cancer service delivery.

The aim of the project is to generate knowledge for wider benefit. Nothing we will produce will necessarily generate income and it is likely that all our tools and outputs will be maximally accessible and free at the point of delivery.

As the IP from this research will relate to methodological approaches and lessons relating to how care for people affected by rare diseases should be organised, we do not anticipate regulatory hurdles associated with medical technologies (e.g. MHRA approval). Barriers to adoption will mainly take the form of stakeholders' lack of awareness of and engagement in the lessons derived from our research. To address this, we will disseminate the findings as widely as possible (as described above).

11. INDEMNITY ARRANGEMENTS

University College London holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. University College London does not accept liability for any breach in the hospital's duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

12. ARCHIVING

UCL and each participating site recognise that there is an obligation to archive study-related documents at the end of the study (as such end is defined within this protocol). SM confirms that he will archive the study master file at University College London for 20 years from study end.

13. PUBLICATION AND DISSEMINATION POLICY

13.1. Projected outputs

Projected outputs from this study include:

- A scoping review of what "centralisation of specialist services" means, and what the elements of centralisation are.
- A taxonomy delineating different models of centralising specialist services, and the context in which they might be applied (e.g., urban or rural location, emergency or non-emergency care).
- Results from the DCE describing the preferences of different stakeholders to centralising specialist services.

13.2. Funder requirements

We will follow the guidance stipulated by the NIHR when communicating our research:

- Notification of outputs and copies of any paper/article should be sent to the funder 28 days before is due to be published.
- The NIHR's contribution should be acknowledged in full by including a funding statement.

- Research articles should be published in journals as open access that make the output available using the Creative Commons Attribution (CC BY) licence, and allow immediate deposit of the final published version in other repositories without restriction on re-use.
- The independent nature of the research and its intellectual property provenance should be emphasised by a disclaimer ("This article/paper/report presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.").

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