

Bangor University

PROFESSIONAL DOCTORATES

Choice in Life (transgender older adults' mental health) and in Death (UK GPs' euthanasia discourses)

Maddock, Emily

Award date:
2017

Awarding institution:
Bangor University

[Link to publication](#)

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12th October 2016

Dear Miss Emily Maddock

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title General Practitioners & the Euthanasia and Assisted Suicide Debate
IRAS reference 197037

The above research project was reviewed by the BCUHB R&D Internal Review Panel.

The Panel is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Document:	Version:	Date:
R&D Form	V5.3.2	26/09/2016
SSI Form	V5.3.2	26/09/2016
Protocol	V1	26/09/2016
Participant Information Sheet	V2	26/09/2016
Consent Form	V2	26/09/2016
Poster advert	V2	26/09/2016
Interview Schedule	V2	26/09/2016
Summary CV: Lamers		2016
Summary CV: Maddock		Undated
Risk Assessment		30/09/2016
Evidence of Insurance		Expires 31/07/2017

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please

go to: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>. Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, I would like to take this opportunity to wish you every success with your research.

Yours sincerely,



Dr. Nefyn Williams PhD, FRCGP
Director of R&D

Copy to:

On behalf of Sponsor:	Mr Hefin Francis School of Psychology Brigantia Building Bangor, Gwynedd LL57 2AS h.francis@bangor.ac.uk
Academic Supervisor:	Dr Carolien Lamers North Wales Clinical Psychology Programme Brigantia Building Bangor, Gwynedd LL57 2DG c.lamers@bangor.ac.uk

Application for Ethical Approval

Project Title: General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

Principal investigator: Maddock, Emily

Other researchers: Lamers, Carolien

Pre-screen Questions

Type of Project

D.Clin.Psy

What is the broad area of research

Clinical/Health

Funding body

Internally Funded

Type of application (check all that apply)

Project requiring scrutiny from an outside body which has its own ethical forms and review procedures

Further details: This application does not require sponsorship from an outside body but requires scrutiny from BCUHB R department.

Proposed methodology (check all that apply)

Other type of research, please specify

Further details: Qualitative research involving interviews

Do you plan to include any of the following groups in your study?

Does your project require use of any of the following facilities and, if so, has the protocol been reviewed by the appropriate expert/safety panel? If yes please complete Part 2:B

If your research requires any of the following facilities MRI, TMS/ tCS, Neurology Panel, has the protocol been reviewed by the appropriate expert/safety panel?

Not applicable (the research does not require special safety panel approval)

Connection to Psychology, (i.e. why Psychology should sponsor the question)

Investigator is a student in Psychology (including the North Wales Clinical Psychology Programme)

Does the research involve NHS patients? (NB: If you are conducting research that requires NHS ethics approval make sure to consult the Psychology Guidelines as you may not need to complete all sections of the Psychology online application)

No

Has this proposal been reviewed by another Bangor University Ethics committee?

No

NHS checklist. Does your study involve any of the following?

Use of NHS Staff or resources e.g. recruitment through the NHS, access to Medical records, use of premises etc.

Further details: The interviews will be undertaken with General Practitioners in North Wales

Part 1: Ethical Considerations

Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?

Yes

Further details: The research is based on interviews, and the background to the study and rationale is included in the 'Research Project Information Sheet' that potential participants will be provided with.

Will you tell participants that their participation is voluntary?

Yes

Further details: This information is included in the 'Research Project Information Sheet' that potential participants will be provided with.

Will you obtain written consent for participation?

Yes

If the research is observational, will you ask participants for their consent to being observed?

N/A

Will you tell participants that they may withdraw from the research at any time and for any reason?

Yes

Further details: This information is included in the 'Research Project Information Sheet' that potential participants will be provided with.

With questionnaires, will you give participants the option of omitting questions they do not want to answer?

N/A

Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?

Yes

Further details: This information is included in the 'Research Project Information Sheet' that potential participants will be provided with.

Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?

Yes

Further details: A debrief will be given at the end of the interview and the option will be given for the participants to receive feedback about the findings of the study.

Will your project involve deliberately misleading participants in any way?

No

Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If *Yes*, give details and state what you will tell them to do should they experience any problems (e.g., who they can contact for help)

No

Further details: Participants will be General Practitioners in Wales who will regularly deal with people at the end of their life, and death and dying. Although euthanasia and assisted suicide are not permitted under the law and therefore interviewees will not be actively engaged in these practices, they are emotive topics that commonly elicit strong views and such could cause some psychological distress. The researcher is a Trainee Clinical Psychologist who regularly works

with clients experiencing emotional distress and would provide further support and advice if necessary (e.g. information about primary care counseling or voluntary support services).

Is there any realistic risk of any participants experiencing discomfort or risk to health, subsequent illness or injury that might require medical or psychological treatment as a result of the procedures?

No

Further details:

Does your project involve work with animals? If *Yes* please complete Part 2: B

No

Does your project involve payment to participants that differs from the normal rates? Is there significant concern that the level of payment you offer for this study will unduly influence participants to agree to procedures they may otherwise find unacceptable? If *Yes* please complete Part 2: B and explain in point 5 of the full protocol

No

If your study involves children under 18 years of age have you made adequate provision for child protection issues in your protocol?

N/A

If your study involves people with learning difficulties have you made adequate provision to manage distress?

N/A

If your study involves participants covered by the Mental Capacity Act (i.e. adults over 16 years of age who lack the mental capacity to make specific decisions for themselves) do you have appropriate consent procedures in place? NB Some research involving participants who lack capacity will require review by an NHS REC. If you are unsure about whether this applies to your study, please contact the Ethics Administrator in the first instance

N/A

If your study involves patients have you made adequate provision to manage distress?

N/A

Does your study involve people in custody?

No

If your study involves participants recruited from one of the Neurology Patient Panels or the Psychiatry Patient Panel then has the protocol been reviewed by the appropriate expert/safety panel?

N/A

If your study includes physically vulnerable adults have you ensured that there will be a person trained in CPR and seizure management at hand at all times during testing?

N/A

Is there significant potential risk to investigator(s) of allegations being made against the investigator(s). (e.g., through work with vulnerable populations or context of research)?

No

Is there significant potential risk to the institution in any way? (e.g., controversy or potential for misuse of research findings.)

No

Part 3: Risk Assessment

Is there significant potential risk to participants of adverse effects?

No

Is there significant potential risk to participants of distress?

No

Is there significant potential risk to participants for persisting or subsequent illness or injury that might require medical or psychological treatment?

No

Is there significant potential risk to investigator(s) of violence or other harm to the investigator(s) (e.g., through work with particular populations or through context of research)?

No

Is there significant potential risk to other members of staff or students at the institution? (e.g., reception or other staff required to deal with violent or vulnerable populations.)

No

Does the research involve the investigator(s) working under any of the following conditions: alone; away from the School; after-hours; or on weekends?

Yes

Further details: The researcher will be following the BCUHB lone worker policy and will make the research supervisor aware of the dates and times of scheduled interviews. Interviews will be carried out inside working hours and at NHS or university premises.

Does the experimental procedure involve touching participants?

No

Does the research involve disabled participants or children visiting the School?

No

Declaration

Declaration of ethical compliance: This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Policy, and that this research will comply with them.

Yes

Declaration of risk assessment The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research.

Yes

Declaration of conflict of interest: To my knowledge, there is no conflict of interest on my part in carrying out this research.

Yes

Part 2: A

The potential value of addressing this issue

Further details: There appears to be a discrepancy between the views of the public and the views of professions (primarily physicians) regarding whether euthanasia (EU) and assisted suicide (AS) should be legalised, with professionals showing less support for EU/AS than the public (Teisseyre, Mullet Sorum, 2005). As such, the UK legislation is more consistent with the views of the professionals than the public (MacDonald, 1998). To gain a deeper understanding of the debate, it is necessary to understand the underlying power relationships and knowledge that may be contributing to the construction on the debate. In a recent study, Lamers and Williams (2015) explored the position and discourses of older adults with regards to the EU/AS debate using Foucauldian discourse analysis. Three discourses emerged, one being 'confused and conflicted' about EU/AS, with their sense of self determination contrasted with the role and influence of others including doctors in this process. Another discourse was related to an aged death, with an evaluation of the value of life in older age. Participants supporting EU/AS also expressed a feeling 'voiceless' in debate discourse, with those perceived as powerful others (physicians/politicians) reluctant to engage in the debate. With these insights, the relationship with a doctor seems to feature highly in the discourses of older people, however, relatively little is known about the position and discourses of UK general practitioners with regards to the EU/AS debate. The proposed study will provide further understanding of the knowledge and power relationships that underlie general practitioners discourses surrounding the EU/AS debate. The proposed study will add to the current knowledge and understanding of the EU/AS debate by illuminating the discourses surrounding EU/AS as a way of understanding the underlying power relationships (relevant to the debate) that are represented by language, and how this constructs, maintains or challenges the power relationships.

Hypotheses

Further details: As this is a qualitative study there are no hypotheses, however, the following questions will be addressed: 1. What is the position of general practitioners in the EU/AS debate? 2. What knowledge and power underlies general practitioners discourses in relation to the euthanasia and assisted suicide debate?

Participants recruitment. Please attach consent and debrief forms with supporting documents

Further details: As social constructionist approaches such as discourse analysis do not require random sampling, recruitment is envisaged to be opportunistic and via supervisor contacts. Six to eight General Practitioners working for Betsi Cadwaladr University Health Board will be required. Participant demographics will be recorded including any recent personal bereavement.

Research methodology

Further details: Interviews will be carried out with the GPs according to the interview schedule (see attached). Interviews will take place at GP surgeries or another mutually convenient venue, lasting approximately 45mins, including debrief and will be recorded using a digital recorder, provided by the North Wales Clinical Psychology Programme. Foucauldian discourse analysis is an approach that attempts to reveal some of the underlying power relationships in society or debates, as they are expressed through language. This approach allows for an understanding of how society/interactions are being shaped and/or constructed by the power relationships that underlie the discourses. Foucauldian discourse analysis is therefore the most appropriate method for understanding the knowledge and power relationships that underlie general practitioners discourses surrounding the EU/AS debate. Foucauldian discourse analysis is an approach rather than a procedure, however, various procedures have been developed in line with the approach. The analysis will follow the procedure outlined by Georgaca and Avdi (2012) in keeping with Lamers and Williams (2015) study. Stages of the analysis will include: • Transcribing the interviews (including vocal tone, pauses and hesitations) and initial coding • Examining the instances when participants mentioned or implied their views re EU/AS, the debate, and their position. • Examining the dynamics of the interaction (discursive agenda) • Establishing the participants position within a

discourse • Determining how a discourse maintains or challenges current practices and power structures • Exploring the impact of the discourse on the participant

Estimated start date and duration of the study.

Further details: The study is part of the researchers D.Clin.Psy and will therefore be completed by the deadline June 2017.

For studies recruiting via SONA or advertising for participants in any way please provide a summary of how participants will be informed about the study in the advertisement. N.B. This should be a brief factual description of the study and what participants will be required to do.

Further details: An advert will be circulated to GP surgeries (see attached). Personal contact with GPs will also be used for recruitment.

Part 2: B

Brief background to the study

The hypotheses

Participants: recruitment methods, age, gender, exclusion/inclusion criteria

Research design

Procedures employed

Measures employed

Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)

Venue for investigation

Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).

Data analysis

Potential offence/distress to participants

Procedures to ensure confidentiality and data protection

**How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)*

Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.

Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)

Payment to: participants, investigators, departments/institutions

Equipment required and its availability

If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

What arrangements are you making to give feedback to participants? The responsibility is yours to provide it, not participants' to request it.

Finally, check your proposal conforms to BPS Guidelines on Ethical Standards in research and sign the declaration. If you have any doubts about this, please outline them.

Part 4: Research Insurance

Is the research to be conducted in the UK?

Yes

Is the research based solely upon the following methodologies? Psychological activity, Questionnaires, Measurements of physiological processes, Venepuncture, Collections of body secretions by non-invasive methods, The administration by mouth of foods or nutrients or variation of diet other than the administration of drugs or other food supplements

Yes

Research that is based solely upon certain typical methods or paradigms is less problematic from an insurance and risk perspective. Is your research based solely upon one or more of these methodologies? Standard behavioural methods such as questionnaires or interviews, computer-based reaction time measures, standardised tests, eye-tracking, picture-pointing, etc; Measurements of physiological processes such as EEG, MEG, MRI, EMG, heart-rate, GSR (not TMS or tCS as they involve more than simple 'measurement'); Collections of body secretions by non-invasive methods, venepuncture (taking of a blood sample), or asking participants to consume foods and/or nutrients (not including the use of drugs or other food supplements or caffeine).

Yes

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
General Practitioners and the euthanasia and assisted suicide debate

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- ☐ England
- ☐ Scotland

- ☒ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

- ☐ IRAS Form
☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☐ Research Ethics Committee
☐ Confidentiality Advisory Group (CAG)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

It looks like your project is research requiring NHS R&D approval but does not require review by a REC within the UK Health Departments Research Ethics Service – is that right?

- ☒ Yes ☐ No

4b. Please confirm the reason(s) why the project does not require review by a REC within the UK Health Departments Research Ethics Service:

- ☐ Projects limited to the use of samples/data samples provided by a Research Tissue Bank (RTB) with generic ethical approval from a REC, in accordance with the conditions of approval.
☐ Projects limited to the use of data provided by a Research Database with generic ethical approval from a REC, in accordance with the conditions of approval.
☐ Research limited to use of previously collected, non-identifiable information
☐ Research limited to use of previously collected, non-identifiable tissue samples within terms of donor consent
☐ Research limited to use of acellular material
☐ Research limited to use of the premises or facilities of care organisations (no involvement of patients/service users as participants)
☒ Research limited to involvement of staff as participants (no involvement of patients/service users as participants)

5. Will any research sites in this study be NHS organisations?

☒ Yes ☐ No

6. Do you plan to include any participants who are children?

☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

☐ Yes ☒ No

9. Is the study or any part of it being undertaken as an educational project?

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):
This research is being undertaken as part of the DClinPsy course.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

Integrated Research Application System

Application Form for Research involving qualitative methods only

NHS/HSC R&D Form (project information)

Please refer to the Submission and Checklist tabs for instructions on submitting R&D applications.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
General Practitioners and the euthanasia and assisted suicide debate

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Emily	Maddock
Address	North Wales Clinical Psychology Programme		
	Brigantia Building		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
E-mail	emilymaddock@yahoo.com		
Telephone	07909643010		
Fax	01248 383718		

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
DClinPsy

Name of educational establishment:
Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title Forename/Initials Surname
	Dr Carolien Lamers
Address	North Wales Clinical Psychology Programme Brigantia Building Bangor, Gwynedd
Post Code	LL57 2DG
E-mail	c.lamers@bangor.ac.uk
Telephone	01248388068
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Emily Maddock	<input type="checkbox"/> Dr Carolien Lamers

A copy of a [current CV](#) for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ☒ Student
☐ Academic supervisor
☐ Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Miss Emily Maddock
Post	Trainee Clinical Psychologist
Qualifications	BSc Psychology with Clinical and Health Psychology - First Class Hons. Postgraduate Certificate in Clinical Applications of Psychology - Merit.
Employer	Betsi Cadwaladr University Health Board
Work Address	North Wales Clinical Psychology Programme Brigantia Building Bangor, Gwynedd
Post Code	LL57 2DG
Work E-mail	psp4f4@bangor.ac.uk
* Personal E-mail	emilymaddock@yahoo.com
Work Telephone	07909643010
* Personal Telephone/Mobile	07909643010
Fax	01248 383718

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a [current CV](#) (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Hefin Francis
Address	School of Psychology Brigantia Building Bangor, Gwynedd
Post Code	LL57 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	01248 388339
Fax	01248 38 2599

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available): N/A

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project
website:

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

☐ Yes ☒ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

Both Euthanasia (EU) and physician assisted suicide (AS) remain illegal in the UK, and are prominent public issues at the center of a heated debate as to whether EU and AS should be legalized. AS is defined as the prescription or

supplying of drugs with the explicit intention of enabling the patient to end their own life. EU is defined as someone other than the patient intentionally ending the life of the patient at the patient's request.

UK professionals show less support for EU/AS than the public and UK legislation is more consistent with the views of professionals. To gain a deeper understanding of the debate, it is necessary to understand the underlying power relationships and knowledge that may be contributing to the construction of the debate. Little is known about the discourses of UK general practitioners (GPs) with regards to the EU/AS debate. Discourses surrounding debates can be useful in understanding the underlying power relationships that are represented by language, and how this constructs, maintains or challenges the power relationships. The proposed study will provide further understanding of the knowledge and power relationships that underlie GPs discourses surrounding the EU/AS debate by addressing the following questions:

1. What is the position of general practitioners in the EU/AS debate?
2. What knowledge and power underlies general practitioners discourses in relation to the euthanasia and assisted suicide debate?

Participants will be six GPs working in North Wales who will take part in interviews following a set schedule. Interviews will be recorded, transcribed and analyzed using Foucauldian discourse analysis. Foucauldian discourse analysis allows for an understanding of how society/interactions are being shaped and/or constructed by the power relationships that underlie discourses.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Ethical issues include that both EU and AS are currently illegal in the UK and there is the potential of participants disclosing information about practice that is unlawful e.g. participating in EU or AS or knowledge of colleague's participation. This will be addressed by gaining informed consent from participants and addressing breaking the bounds of confidentiality and that action will be taken if such a disclosure is made. Disclosure of any practice that is unlawful or the possibility of this will result in consulting the police and the General Medical Council. The interview schedule includes questions which relate to the meaning of EU and AS for the participant but does not include questions relating to professional practice or conduct e.g. being asked about EU/AS by a patient.

There is potential that the sensitive nature of the topic and interview questions could cause the participants distress. To address this, there will be a debrief at the end of the interviews and a debrief form will be provided with information about accessing further support.

To address these issues, the following information has been included in the 'Research Project Information Sheet' (see attached) that will be provided to potential participants in order for them to make an informed decision about participation:

What are the potential risks in taking part in the research?

We do not anticipate any risks in taking part in the project. However, euthanasia and assisted suicide are emotive topics and the interview could remind you of experiences that are related to death and dying. You can of course end the interview at any time without giving an explanation. If you feel that you would like further advice and support, information about relevant agencies can be discussed with you.

All information that you provide will be strictly confidential. However, if you share information that might be considered unlawful to the interviewer, Emily will discuss this with you and if required relevant organizations and bodies will be informed.

Emily will be adhering to strict confidentiality rules, and will transcribe the interview. Any paperwork and recordings will be kept in a locked cabinet at the University and the transcripts on a password protected laptop. The interview will be wiped of the recorder and the laptop, and any paperwork destroyed, in line with data protection legislation and Bangor University policies. Your interview will be used in the write up of the project but you will not be named and any identifying factors will be anonymized.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☒ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

The following questions will be addressed:

1. What is the position of General Practitioners in the euthanasia and assisted suicide debate?
2. What knowledge and power underlies General Practitioners discourses in relation to the euthanasia and assisted suicide debate?

As this is a qualitative study there are no hypotheses.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

N/A

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

The scientific justification for the study includes:

There appears to be a discrepancy between the views of the public and the views of professions (primarily physicians) regarding whether euthanasia (EU) and assisted suicide (AS) should be legalised, with professionals showing less support for EU/AS than the public (Teisseyre, Mullet & Sorum, 2005). As such, the UK legislation is more consistent with the views of the professionals than the public (MacDonald, 1998). To gain a deeper understanding of the debate, it is necessary to understand the underlying power relationships and knowledge that may be contributing to the construction on the debate. In a recent study, Lamers and Williams (2015) explored the position and discourses of older adults with regards to the EU/AS debate using Foucauldian discourse analysis. Three discourses emerged, one being 'confused and conflicted' about EU/AS, with their sense of self determination contrasted with the role and influence of others including doctors in this process. Another discourse was related to an aged death, with an evaluation of the value of life in older age. Participants supporting EU/AS also expressed a feeling 'voiceless' in debate discourse, with those perceived as powerful others (physicians/politicians) reluctant to engage in the debate. With these insights, the relationship with a doctor seems to feature highly in the discourses of older people, however, relatively little is known about the position and discourses of UK general practitioners with regards to the EU/AS debate. The proposed study will provide further understanding of the knowledge and power relationships that underlie general practitioners discourses surrounding the EU/AS debate. The proposed study will add to the current knowledge and understanding of the EU/AS debate by illuminating the discourses surrounding EU/AS as a way of understanding the underlying power relationships (relevant to the debate) that are represented by language, and how this constructs,

maintains or challenges the power relationships.

This Study forms part of the researchers DClinPsy and therefore has an educational value in further developing the researchers qualitative research skills.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

As this is a qualitative study there are no hypotheses, however, the following questions will be addressed:

1. What is the position of general practitioners in the EU/AS debate?
2. What knowledge and power underlies general practitioners discourses in relation to the euthanasia and assisted suicide debate?

As social constructionist approaches such as discourse analysis do not require random sampling, recruitment is envisaged to be opportunistic via advertisement (see attached) and via supervisor contacts.

Six to eight General Practitioners (working for Betsi Cadwaladr University Health Board/retired/locum clinicians) will be required. Participant demographics will be recorded including any recent personal bereavement and if the GP has ever been approached/asked about euthanasia or assisted suicide by a patient.

Interviews will be carried out with the GPs according to the interview schedule (see attached). Interviews will take place at GP surgeries or another mutually convenient venue, lasting approximately 45mins, including debrief and will be recorded using a digital recorder, provided by the North Wales Clinical Psychology Programme.

Foucauldian discourse analysis is an approach that attempts to reveal some of the underlying power relationships in society or debates, as they are expressed through language. This approach allows for an understanding of how society/interactions are being shaped and/or constructed by the power relationships that underlie the discourses. Foucauldian discourse analysis is therefore the most appropriate method for understanding the knowledge and power relationships that underlie general practitioners discourses surrounding the EU/AS debate. Foucauldian discourse analysis is an approach rather than a procedure, however, various procedures have been developed in line with the approach. The analysis will follow the procedure outlined by Georgaca and Avdi (2012) in keeping with Lamers and Williams (2015) study. Stages of the analysis will include:

- Transcribing the interviews (including vocal tone, pauses and hesitations) and initial coding
- Examining the instances when participants mentioned or implied their views re EU/AS, the debate, and their position.
- Examining the dynamics of the interaction (discursive agenda)
- Establishing the participants position within a discourse
- Determining how a discourse maintains or challenges current practices and power structures
- Exploring the impact of the discourse on the participant

The study is part of the researchers D.Clin.Psy and will therefore be completed by the deadline June 2017.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☒ Design of the research
- ☒ Management of the research
- ☒ Undertaking the research
- ☒ Analysis of results
- ☒ Dissemination of findings
- ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.

As the research does not involve patients or carers, the research proposal was reviewed and commented on by the DClinPsy people panel.

4. RISKS AND ETHICAL ISSUES**RESEARCH PARTICIPANTS****A15. What is the sample group or cohort to be studied in this research?**

Select all that apply:

- ☐ Blood
- ☐ Cancer
- ☐ Cardiovascular
- ☐ Congenital Disorders
- ☐ Dementias and Neurodegenerative Diseases
- ☐ Diabetes
- ☐ Ear
- ☐ Eye
- ☐ Generic Health Relevance
- ☐ Infection
- ☐ Inflammatory and Immune System
- ☐ Injuries and Accidents
- ☐ Mental Health
- ☐ Metabolic and Endocrine
- ☐ Musculoskeletal
- ☐ Neurological
- ☐ Oral and Gastrointestinal
- ☐ Paediatrics
- ☐ Renal and Urogenital
- ☐ Reproductive Health and Childbirth
- ☐ Respiratory
- ☐ Skin
- ☐ Stroke

Gender: Male and female participants

Lower age limit: 18 Years

Upper age limit: Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

General Practitioners (employed by Betsi Cadwaladr University Health Board/retired/locum)

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

None

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Invitation to participate	4	0	10mins	The Main researcher (Emily Maddock) and supervisor (Carolien Lamers) will disseminate the invitations/information sheets for GPs to read
Informed consent	4	0	10mins	The Main researcher will gain informed consent via discussion and completing the informed consent form with GPs who wish to participate. time will be allowed for questions. This will happen at the beginning of the interview.
Voice recorded interview, following a schedule	4	0	45mins	The main researcher will conduct the interviews at GP Surgeries, Bangor University or another mutually agreed location. Interviews will be recorded on a Dictaphone.
Debrief	4	0	5-10mins	The main researcher will complete the debrief at the end of the interview
Outcome feedback	5	0	10mins	Participants will have the option of receiving a written summary of the findings. Written and sent by the main researcher.

A21. How long do you expect each participant to be in the study in total?

The contact time will be approximately one hour including reading the information sheet, giving consent to participate, participating in the interview and debrief. It will be a period of approximately 4-5 months before the optional feedback information will be available. Those wishing not to receive the feedback will have no further contact after the interview.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Participants will be General Practitioners in Wales who will regularly deal with people at the end of their life, and death and dying. Although euthanasia and assisted suicide are not permitted under the law and therefore interviewees will not be actively engaged in these practices, they are emotive topics that commonly elicit strong views and and such could cause some psychological distress. The researcher is a Trainee Clinical Psychologist who regularly works with clients experiencing emotional distress and would provide further support and advice if necessary (e.g. information about primary care counseling or voluntary support services).

Potential benefits include that participants will have an opportunity to discuss and have their views heard, which they may not otherwise have.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☒ Yes ☐ No

If Yes, please give details of procedures in place to deal with these issues:

Participants will be General Practitioners in Wales who will regularly deal with people at the end of their life, and death and dying. Although euthanasia and assisted suicide are not permitted under the law and therefore interviewees will not be actively engaged in these practices, they are emotive topics that commonly elicit strong

views and and such could cause some psychological distress. The researcher is a Trainee Clinical Psychologist who regularly works with clients experiencing emotional distress and would provide further support and advice if necessary (e.g. information about primary care counseling or voluntary support services).

Informed consent will be gained from participants (see informed consent form) which addresses breaking the bounds of confidentiality and that action will be taken if disclosure of any practice that is unlawful is made. This will result in consulting the police and the General Medical Council. The interview schedule includes questions which relate to the meaning of EU and AS for the participant but does not include questions relating to professional practice or conduct e.g. being asked about EU/AS by a patient.

A24. What is the potential for benefit to research participants?

The participants may benefit from having the opportunity to discuss and have their views on EU and AS heard.

A26. What are the potential risks for the researchers themselves? (if any)

Lone working - The researcher will be following the BCUHB lone worker policy and will make the research supervisor aware of the dates and times of scheduled interviews. Interviews will be carried out inside working hours and at NHS or university premises.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

As social constructionist approaches such as discourse analysis do not require random sampling, recruitment will be opportunistic and via supervisor contacts with GP surgeries. An advert (see attached) for research participation will be circulated to GP surgeries to aid recruitment. This process will be completed by the main researcher, Emily Maddock and Carolien Lamers (supervisor).

Resources such as envelopes and postage will be covered by North Wales Clinical Psychology Programme.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☐ Yes ☒ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

☒ Yes ☐ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

An advert will be circulated to GP surgeries via email and supervisor contacts (see attached).

A29. How and by whom will potential participants first be approached?

Potential participants may have seen the advert and contacted the researcher via the email address provided. In this situation the researcher (Emily Maddock) will respond to the email providing further information (e.g. the information sheet; see attached) and arrange an interview date if appropriate. Supervisor contacts (local GPs) will be emailed the

relevant advert and information sheets to be made aware of the study. Emails will be sent by Emily Maddock &/or Carolien Lamers.

A30-1. Will you obtain informed consent from or on behalf of research participants?

☒ Yes ☐ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Emily Maddock will email informed consent forms (see attached) to potential participants who have expressed an interest, to read, initial and return. Answers to any participant questions will be given. An interview will then be scheduled and a paper copy of the completed informed consent form will be signed by the participant, at the beginning of the interview. Participants have the option to have a copy of the completed form. This process is detailed on the participant information sheet (see attached).

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

☒ Yes ☐ No

A31. How long will you allow potential participants to decide whether or not to take part?

A deadline for responding will be included on the advert and on emails sent to supervisor contacts. This is 4 weeks from the advert and emails being sent out.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

Unfortunately the researcher is not Welsh speaking so interviews will be carried out in English. This information has been included on the participant information sheet. It is not anticipated that verbal comprehension will be a difficulty with the participants in this study.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

The optional written feedback on the outcome of the study can be provided in Welsh with the use of the University translation service. Other documentation e.g. the advert, the information sheet and consent form will be translated to Welsh following ethics approval, but the interview with the researcher will be through the medium of English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- ☐ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.

☒ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☐ Storage of personal data on any of the following:
 - ☐ Manual files (includes paper or film)
 - ☐ NHS computers
 - ☐ Social Care Service computers
 - ☐ Home or other personal computers
 - ☒ University computers
 - ☐ Private company computers
 - ☐ Laptop computers

Further details:

Interviews will be transcribed from the Dictaphone onto an encrypted University laptop and then deleted from the Dictaphone. Data including transcripts will be stored on an encrypted USB device supplied by the DClinPsy programme. All paper work including consent forms etc. will be stored in a locked draw in the supervisor's office at Bangor University.

A37. Please describe the physical security arrangements for storage of personal data during the study?

All paper work including consent forms etc. will be stored in a locked draw in the supervisor's office at Bangor University.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Interviews will be transcribed from the Dictaphone onto an encrypted laptop and then deleted from the Dictaphone.

Data including transcripts will be stored on an encrypted USB device supplied by the DClinPsy programme. All paper work including consent forms etc. will be stored in a locked draw in the supervisor's office at Bangor University.

Each participant will be allocated a pseudonym which will be used for the purposes of writing up the findings of the study and publication. Any other identifiable information such as surgery location will be removed.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

The main researcher - Emily Maddock
The researchers supervisor - Dr Carolien Lamers

This information is included in the information and informed consent sheets.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The anonymized data will be analysed by Emily Maddock and Carolien Lamers at Bangor University on an encrypted laptop and stored on an encrypted memory stick provided by the DClinPsy programme.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title Forename/Initials Surname
	Miss Emily Maddock
Post	Trainee Clinical Psychologist
Qualifications	BSc. Hons. Psychology with Clinical and Health Psychology
Work Address	North Wales Clinical Psychology Programme
	Brigantia Building
	Bangor, Gwynedd
Post Code	LL57 2DG
Work Email	psp4f4@bangor.ac.uk
Work Telephone	
Fax	

A43. How long will personal data be stored or accessed after the study has ended?

- ☒ Less than 3 months
☐ 3 – 6 months
☐ 6 – 12 months
☐ 12 months – 3 years
☐ Over 3 years

A44. For how long will you store research data generated by the study?

Years:

Months: 6

A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

As this study forms part of a DClinPsy qualification, the data will be destroyed following completion of the qualification.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

☐ Yes ☒ No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

☐ Yes ☒ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

☐ Yes ☒ No

Please give details, or justify if not registering the research.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- ☒ Peer reviewed scientific journals
- ☐ Internal report
- ☒ Conference presentation

- ☐ Publication on website
- ☒ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Pseudonyms will be used when reporting participant quotes, any identifiable information will be removed from quotes (such as information that could indicate location).

A53. Will you inform participants of the results?

☒ Yes ☐ No

Please give details of how you will inform participants or justify if not doing so.

Participants will be given the option to receive a written summary of the result (Welsh translation will be available) or to have an oral presentation of the results.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- ☒ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☐ Review within the Chief Investigator's institution or host organisation
- ☒ Review within the research team
- ☒ Review by educational supervisor
- ☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

As this research is part of a DClinPsy, the study proposal has been reviewed by the DClinPsy research team and the research supervisor. The study has also been reviewed by the Bangor University Ethics Committee.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 6
 Total international sample size (including UK): 0
 Total in European Economic Area: 0

Further details:

Qualitative studies do not require large sample sizes and six participants is considered to be suitable. Larger

numbers would not be an effective use of the researchers or participants time. Opportunistic or snowballing recruitment techniques will be used.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Qualitative studies do not require large sample sizes and six participants is considered to be suitable. Larger numbers would not be an effective use of the researchers or participants time. Opportunistic or snowballing recruitment techniques will be used.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Foucauldian discourse analysis is an approach that attempts to reveal some of the underlying power relationships in society or debates, as they are expressed through language. This approach allows for an understanding of how society/interactions are being shaped and/or constructed by the power relationships that underlie the discourses. Foucauldian discourse analysis is therefore the most appropriate method for understanding the knowledge and power relationships that underlie general practitioners discourses surrounding the EU/AS debate. Foucauldian discourse analysis is an approach rather than a procedure, however, various procedures have been developed in line with the approach. The analysis will follow the procedure outlined by Georgaca and Avdi (2012) in keeping with Lamers and Williams (2015) study. Stages of the analysis will include:

- Transcribing the interviews (including vocal tone, pauses and hesitations) and initial coding
- Examining the instances when participants mentioned or implied their views re EU/AS, the debate, and their position.
- Examining the dynamics of the interaction (discursive agenda)
- Establishing the participants position within a discourse
- Determining how a discourse maintains or challenges current practices and power structures
- Exploring the impact of the discourse on the participant

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname
	Dr Carolien Lamers
Post	Consultant Clinical Psychologist, Clinical Lecturer
Qualifications	Doctorandus Social Gerontology, Catholic University Nijmegen, Netherlands Doctorate in Clinical Psychology, Bangor University, UK
Employer	North Wales Clinical Psychology Programme
Work Address	Brigantia, Penrallt Road, Bangor University Bangor Gwynedd
Post Code	LL57 2DG
Telephone	01248388068
Fax	
Mobile	
Work Email	c.lamers@bangor.ac.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead SponsorStatus: ☐ NHS or HSC care organisation

Commercial status:

☒ Academic☐ Pharmaceutical industry☐ Medical device industry☐ Local Authority☐ Other social care provider (including voluntary sector or private organisation)☐ Other*If Other, please specify:***Contact person**

Name of organisation Bangor University

Given name Hefin

Family name Francis

Address School of Psychology

Town/city Brigantia Building

Post code LL57 2AS

Country UNITED KINGDOM

Telephone 01248 388339

Fax 01248 38 2599

E-mail h.francis@bangor.ac.uk

Is the sponsor based outside the UK?☐ Yes ☒ No*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.***A65. Has external funding for the research been secured?**☐ Funding secured from one or more funders☐ External funding application to one or more funders in progress☒ No application for external funding will be made

What type of research project is this?

☐ Standalone project☐ Project that is part of a programme grant☐ Project that is part of a Centre grant☒ Project that is part of a fellowship/ personal award/ research training award☐ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if applicable.

☐ Yes ☒ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

☐ Yes ☒ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Miss Debra Slater
Organisation	BCUHB
Address	Research Governance c/o Ysbty Gwynedd Bangor
Post Code	LL57 2PW
Work Email	debra.slater@wales.nhs.uk
Telephone	01248384877
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/10/2016

Planned end date: 01/06/2017

Total duration:

Years: 0 Months: 7 Days: 1

A71-1. Is this study?

☒ Single centre
☐ Multicentre

A71-2. Where will the research take place? (Tick as appropriate)

☐ England
☐ Scotland
☒ Wales

- ☐ Northern Ireland
- ☐ Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?

☐ Yes ☒ No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- ☐ NHS organisations in England
- ☐ NHS organisations in Wales
- ☐ NHS organisations in Scotland
- ☐ HSC organisations in Northern Ireland
- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☐ Joint health and social care agencies (eg community mental health teams)
- ☐ Local authorities
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☐ Probation areas
- ☐ Independent (private or voluntary sector) organisations
- ☒ Educational establishments 1
- ☐ Independent research units
- ☐ Other (give details)

Total UK sites in study: 1

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

☐ Yes ☒ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

There will be regular meetings with the research supervisor and regular research updates to the research team. The research is formally assessed via Viva Voce.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the

sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Bangor University insurance will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Bangor University insurance will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- ☒ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- ☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

- ☐ Yes ☒ No ☐ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	BCUHB	Title	Miss
Department name	GP Practices across BCUHB	First name/ Initials	Emily
Street address	C/O Ysbyty Gwynedd	Surname	Maddock
Town/city	Bangor		
Post Code	LL57 2PW		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - ◊ Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - ◊ May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - ◊ May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - ◊ Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - ◊ May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

☐ Chief Investigator

- ☐ Sponsor
- ☐ Study co-ordinator
- ☐ Student
- ☐ Other – please give details
- ☐ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Emily Maddock on 26/09/2016 11:24.

Job Title/Post: Trainee Clinical Psychologist

Organisation: BCUHB

Email: psp4f4@bangor.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Mr Hefin Francis on 26/09/2016 12:28.

Job Title/Post: School Manager for Psychology
 Organisation: Bangor University
 Email: h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by carolien Lamers on 26/09/2016 12:14.

Job Title/Post:	Consultant Clinical Psychologist/ Admissions tutor
Organisation:	North Wales Clinical Psychology Programme
Email:	c.lamers@bangor.ac.uk

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
General Practitioners and the euthanasia and assisted suicide debate

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located?(Tick all that apply)

- ☐ England
- ☐ Scotland

- ☒ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

- ☐ IRAS Form
☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☐ Research Ethics Committee
☐ Confidentiality Advisory Group (CAG)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

It looks like your project is research requiring NHS R&D approval but does not require review by a REC within the UK Health Departments Research Ethics Service – is that right?

- ☒ Yes ☐ No

4b. Please confirm the reason(s) why the project does not require review by a REC within the UK Health Departments Research Ethics Service:

- ☐ Projects limited to the use of samples/data samples provided by a Research Tissue Bank (RTB) with generic ethical approval from a REC, in accordance with the conditions of approval.
☐ Projects limited to the use of data provided by a Research Database with generic ethical approval from a REC, in accordance with the conditions of approval.
☐ Research limited to use of previously collected, non-identifiable information
☐ Research limited to use of previously collected, non-identifiable tissue samples within terms of donor consent
☐ Research limited to use of acellular material
☐ Research limited to use of the premises or facilities of care organisations (no involvement of patients/service users as participants)
☒ Research limited to involvement of staff as participants (no involvement of patients/service users as participants)

5. Will any research sites in this study be NHS organisations?

☒ Yes ☐ No

6. Do you plan to include any participants who are children?

☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

☐ Yes ☒ No

9. Is the study or any part of it being undertaken as an educational project?

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):
This research is being undertaken as part of the DClinPsy course.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

Site-Specific Information Form (NHS sites)

Is the site hosting this research a NHS site or a non-NHS site? *NHS sites include Health and Social Care organisations in Northern Ireland. The sites hosting the research are the sites in which or through which research procedures are conducted. For NHS sites, this includes sites where NHS staff are participants.*

- ☒ NHS site
☐ Non-NHS site

This question must be completed before proceeding. The filter will customise the form, disabling questions which are not relevant to this application.

One Site-Specific Information Form should be completed for each research site and submitted to the relevant R&D office with the documents in the checklist. See guidance notes.

The data in this box is populated from Part A:

Title of research:

General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

Short title: General Practitioners and the euthanasia and assisted suicide debate

Chief Investigator: Title Forename/Initials Surname
Miss Emily Maddock

Name of NHS Research Ethics Committee to which application for ethical review is being made:

Project reference number from above REC:

1-1. Give the name of the NHS organisation responsible for this research site

Betsi Cadwaladr University Health Board

1-3. In which country is the research site located?

- ☐ England
☒ Wales
☐ Scotland
☐ Northern Ireland

1-4. Is the research site a GP practice or other Primary Care Organisation?

- ☒ Yes ☐ No

If Yes, please give the name of the research site:
GP Practices TBA

2. Who is the Principal Investigator or Local Collaborator for this research at this site?

Select the appropriate title: ☒ Principal Investigator
☐ Local Collaborator

	Title Forename/Initials Surname
	Miss Emily Maddock
Post	Trainee Clinical Psychologist
Qualifications	BSc Psychology with Clinical and Health Psychology - First Class Hons. Postgraduate Certificate in Clinical Applications of Psychology - Merit.
Organisation	Betsi Cadwaladr University Health Board
Work Address	North Wales Clinical Psychology Programme Brigantia Building Bangor, Gwynedd
PostCode	LL57 2DG
Work E-mail	emilymaddock@yahoo.com
Work Telephone	07909643010
Mobile	07909643010
Fax	01248 383718

a) Approximately how much time will this person allocate to conducting this research? *Please provide your response in terms of Whole Time Equivalents (WTE).*
 0.4wte

b) Does this person hold a current substantive employment contract, Honorary Clinical Contract or Honorary Research Contract with the NHS organisation or accepted by the NHS organisation? ☒ Yes ☐ No

A copy of a current CV for the Principal Investigator (maximum 2 pages of A4) must be submitted with this form.

3. Please give details of all locations, departments, groups or units at which or through which research procedures will be conducted at this site and describe the activity that will take place.

Please list all locations/departments etc where research procedures will be conducted within the NHS organisation, describing the involvement in a few words. Where access to specific facilities will be required these should also be listed for each location.

Name the main location/department first. Give details of any research procedures to be carried out off site, for example in participants' homes.

	Location	Activity/facilities
1	GP Practices across BCUHB	Inform Consent Interview Debrief

5. Please give details of all other members of the research team at this site.

1

	Title Forename/Initials Surname
	Dr Carolien Lamers
Work E-mail	c.lamers@bangor.ac.uk

Employing organisation: BCUHB
 Post: Clinical Psychologist
 Qualifications: Doctorate in Clinical Psychology
 Role in research team: researcher

a) Approximately how much time (approximately) will this person allocate to conducting this research? *Please provide your response in terms of Whole Time Equivalents (WTE).*

0.05wte

b) Does this person hold a current substantive employment contract, Honorary Clinical Contract or Honorary Research Contract with the NHS organisation or accepted by the NHS organisation?

☒ Yes ☐ No

A copy of a current CV for the research team member (maximum 2 pages of A4) must be submitted to the R&D office.

6. Does the Principal Investigator or any other member of the site research team have any direct personal involvement (e.g. financial, share-holding, personal relationship etc) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

7. What is the proposed local start and end date for the research at this site?

Start date: 01/10/2016

End date: 01/06/2017

Duration (Months): 8

8-1. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *(These include seeking consent, interviews, non-clinical observations and use of questionnaires.)*

Columns 1-4 have been completed with information from A18 as below:

- 1. Total number of interventions/procedures to be received by each participant as part of the research protocol.*
- 2. If this intervention would have been routinely given to participants as part of their care, how many of the total would have been routine?*
- 3. Average time taken per intervention (minutes, hours or days)*
- 4. Details of who will conduct the procedure, and where it will take place*

Please complete Column 5 with details of the names of individuals or names of staff groups who will conduct the procedure at this site.

Intervention or procedure	1	2	3	4	5
Invitation to participate	4	0	10mins	The Main researcher (Emily Maddock) and supervisor (Carolien Lamers) will disseminate the invitations/information sheets for GPs to read	Emily Maddock Carolien Lamers
Informed consent	4	0	10mins	The Main researcher will gain informed consent via discussion and completing the informed consent form with GPs who wish to participate. time will be allowed for	Emily Maddock Carolien Lamers

			questions. This will happen at the beginning of the interview.		
Voice recorded interview, following a schedule	4	0	45mins	The main researcher will conduct the interviews at GP Surgeries, Bangor University or another mutually agreed location. Interviews will be recorded on a Dictaphone.	Emily Maddock
Debrief	4	0	5-10mins	The main researcher will complete the debrief at the end of the interview	Emily Maddock Carolien Lamers
Outcome feedback	5	0	10mins	Participants will have the option of receiving a written summary of the findings. Written and sent by the main researcher.	Emily Maddock Carolien Lamers

8-2. Will any aspects of the research at this site be conducted in a different way to that described in Part A or the protocol?

☐ Yes ☒ No

If Yes, please note any relevant changes to the information in the above table.

Are there any changes other than those noted in the table?

10. How many research participants/samples is it expected will be recruited/obtained from this site?

6-8

11. Give details of how potential participants will be identified locally and who will be making the first approach to them to take part in the study.

GP's will be identified via opportunistic sampling, and provided with the study advert via email by the researcher.

12. Who will be responsible for obtaining informed consent at this site? What expertise and training do these persons have in obtaining consent for research purposes?

Name	Expertise/training
Emily Maddock	Training via undergraduate degree and routine practice during clinical work.
Carolien Lamers	Training via undergraduate degree, previous research and routine practice during clinical work.

15-1. Is there an independent contact point where potential participants can seek general advice about taking part in research?

British Psychological Society - details will be given during informed consent process.

Tel: +44 (0)116 254 9568

Email: enquiries@bps.org.uk

15-2. Is there a contact point where potential participants can seek further details about this specific research project?

North Wales Clinical Psychology Programme

Tel: 01248 388365

Hefin Francis - Bangor University

Email: h.francis@bangor.ac.uk

16. Are there any changes that should be made to the generic content of the information sheet to reflect site-specific issues in the conduct of the study? A substantial amendment may need to be discussed with the Chief Investigator and submitted to the main REC.

Non-foreseen

Please provide a copy on headed paper of the participant information sheet and consent form that will be used locally. Unless indicated above, this must be the same generic version submitted to/approved by the main REC for the study while including relevant local information about the site, investigator and contact points for participants (see guidance notes).

17. What local arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters etc.)

Any special communication needs will be addressed as necessary.

18. What local arrangements will be made to inform the GP or other health care professionals responsible for the care of the participants?

Due to the nature of the study the GP will not need to be informed.

19. What arrangements (e.g. facilities, staffing, psychosocial support, emergency procedures) will be in place at the site, where appropriate, to minimise the risks to participants and staff and deal with the consequences of any harm?

The rooms that will be used for interviews will be private and considered fit for purpose.

20. What are the arrangements for the supervision of the conduct of the research at this site? Please give the name and contact details of any supervisor not already listed in the application.

The researcher will meet with Carolien (supervisor) regularly to ensure conduct policy is being adhered to.

21. What external funding will be provided for the research at this site?

- ☐ Funded by commercial sponsor
- ☐ Other funding
- ☒ No external funding

How will the costs of the research be covered?

GP's will give their time voluntarily.

Costs will be covered by Bangor University e.g. printing/mileage.

23. Authorisations required prior to R&D approval

The local research team are responsible for contacting the local NHS R&D office about the research project. Where the research project is proposed to be coordinated centrally and therefore there is no local research team, it is the responsibility of the central research team to instigate this contact with local R&D.

NHS R&D offices can offer advice and support on the set-up of a research project at their organisation, including information on local arrangements for support services relevant to the project. These support services may include clinical supervisors, line managers, service managers, support department managers, pharmacy, data protection officers or finance managers depending on the nature of the research.

Obtaining the necessary support service authorisations is not a pre-requisite to submission of an application for NHS research permission, but all appropriate authorisations must be in place before NHS research permission will be granted. Processes for obtaining authorisations will be subject to local arrangements, but the minimum expectation is that the local R&D office has been contacted to notify it of the proposed research project and to discuss the project's needs **prior** to submission of the application for NHS research permission via IRAS.

Failure to engage with local NHS R&D offices **prior** to submission may lead to unnecessary delays in the process of this application for NHS research permissions.

Declaration:

☒ I confirm that the relevant NHS organisation R&D office has been contacted to discuss the needs of the project and local arrangements for support services. I understand that failure to engage with the local NHS R&D office before submission of this application may result in unnecessary delays in obtaining NHS research permission for this project.

Please give the name and contact details for the NHS R&D office staff member you have discussed this application with:

Please note that for some sites the NHS R&D office contact may not be physically based at the site. For contact details refer to the guidance for this question.

	Title	Forename/Initials	Surname
	Miss	Debra	Slater
Work E-mail	debra.slater@wales.nhs.uk		
Work Telephone	01248384877		

Declaration by Principal Investigator or Local Collaborator

1. The information in this form is accurate to the best of my knowledge and I take full responsibility for it.
2. I undertake to abide by the ethical principles underpinning the World Medical Association's Declaration of Helsinki and relevant good practice guidelines in the conduct of research.
3. If the research is approved by the main REC and NHS organisation, I undertake to adhere to the study protocol, the terms of the application of which the main REC has given a favourable opinion and the conditions requested by the NHS organisation, and to inform the NHS organisation within local timelines of any subsequent amendments to the protocol.
4. If the research is approved, I undertake to abide by the principles of the Research Governance Framework for Health and Social Care.
5. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to the conduct of research.
6. I undertake to disclose any conflicts of interest that may arise during the course of this research, and take responsibility for ensuring that all staff involved in the research are aware of their responsibilities to disclose conflicts of interest.
7. I understand and agree that study files, documents, research records and data may be subject to inspection by the NHS organisation, the sponsor or an independent body for monitoring, audit and inspection purposes.
8. I take responsibility for ensuring that staff involved in the research at this site hold appropriate contracts for the duration of the research, are familiar with the Research Governance Framework, the NHS organisation's Data Protection Policy and all other relevant policies and guidelines, and are appropriately trained and experienced.
9. I undertake to complete any progress and/or final reports as requested by the NHS organisation and understand that continuation of permission to conduct research within the NHS organisation is dependent on satisfactory completion of such reports.
10. I undertake to maintain a project file for this research in accordance with the NHS organisation's policy.
11. I take responsibility for ensuring that all serious adverse events are handled within the NHS organisation's policy for reporting and handling of adverse events.

12. I understand that information relating to this research, including the contact details on this application, will be held by the R&D office and may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
13. I understand that the information contained in this application, any supporting documentation and all correspondence with the R&D office and/or the REC system relating to the application will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

This section was signed electronically by Miss Emily Maddock on 26/09/2016 11:08.

Job Title/Post: Trainee Clinical Psychologist

Organisation: BCUHB

Email: psp4f4@bangor.ac.uk

The Legislation: If you are older and trans or non-binary, you may have two 'protected characteristics' under the Equality Act 2010. Care providers must not discriminate against you and they must not harass you. The Human Rights Act 1998, also protects your privacy and dignity. The NHS Constitution supports your right to make personal choices and decisions.

Ageing generally: It's important to keep as physically and mentally fit as possible. Eat a balanced diet, keep alcohol to no more than 14 units a week; don't take non-prescribed drugs and, above all, watch your weight and don't smoke. These factors raise the risk of cancer, heart and circulatory diseases which are the main causes of death in the UK. Smoking also damages the skin and increases wrinkles and, in trans women, it makes oestrogen less effective. For more detailed information, see the Public Health England factsheet in this series, and:

- ▶ [NHS - Alcohol Misuse](#)
- ▶ www.londonfriend.org.uk/antidote
- ▶ [NHS - Stop Smoking Treatments](#)

Exercise helps to protect you against dementia as well as other illnesses. If you are not able to do vigorous exercise, try yoga classes. If you play a wind-instrument, or you like singing, join a band or a choir. This can be a good way of exercising your lungs, as well as socialising. Keep your brain active: read, join adult education classes, and do crosswords.

Long-term conditions: Take care of any long-term conditions, such as diabetes or HIV. Osteoporosis is less of a risk if you continue to take hormones and Vitamin D and calcium supplements. If you are not taking hormones, you should be screened for osteoporosis.

Cancer Risks: In addition to the risks mentioned above, be aware of any history of particular cancers in your family. Note that screening is not automatic for breast and genital cancers if you are no longer registered according to your birth sex, or if you are a trans man who has had chest reconstruction.

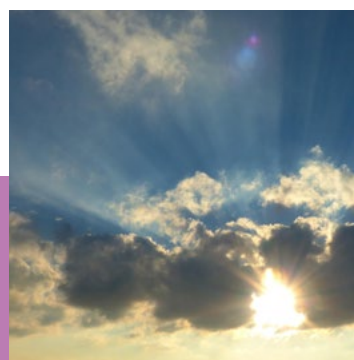
Breast care (cancer): Trans men and trans women should check breasts for lumps, inverted nipples or discharge. Tell your GP if you spot any of these symptoms. Trans women with implants should tell the radiologist before having a mammogram; just like any other woman with implants, you may need alternative screening.

- ▶ www.cancerscreening.nhs.uk/breastscreen

Trans men: If you have a cervix, remind your GP that you need smear tests. (You may wish to insert the speculum yourself & lie on your side).

- ▶ www.cancerscreening.nhs.uk/cervical

If you have a family history of cancer of the uterus and ovaries, and haven't had yours removed, you should have pelvic examinations regularly (3 yearly; or more often if you have polycystic ovaries).



Trans Health Factsheet on Ageing - Rising to the challenge

Trans women: Prostate glands can become cancerous. Low testosterone levels won't keep you safe from other kinds of cancer.

► www.cancerscreening.nhs.uk/prostate

General genital care: Your needs will vary depending on any surgery you have had, and whether or not you are sexually active. Both trans men and trans women (and/or their partners) and those who are non-binary should use condoms and lubricant, because older genital tissue is more vulnerable to damage and infection.

Trans men following phalloplasty should report any difficulty in peeing; the urethra may be blocked. Erectile prostheses last roughly 7 years - keep the date in the diary. Trans women, to prevent the vagina closing, should continue dilating unless you are having penetrative sex.

Residential and End of Life Care: NHS Regulations (2014): "care is focused on dying people's wishes - rather than processes. This will make sure that their voices, and those of their families, are heard at all times." Families are defined as "the people important to the dying person". Decisions about care are "in accordance with the person's needs and wishes". "Care is tailored to the individual and delivered with compassion"; "comfort and dignity is prioritised". You may, for instance, specify whether you wish personal care to be undertaken by a man or a woman.

Your legal entitlements to protection continue. Age UK provides information about trans issues in later life:

► [Factsheet Transgender issues and later life](#)

An "individual care plan" (a kind of living-will) is suggested:

► [Department of health: New approach to care for the dying published](#)

Writing an Individual Care Plan: If you haven't already written a Care Plan, you should do it now, to ensure that you will be treated according to your wishes, by those providing care for you both before and after your death. Make sure that you always have a copy of your Plan on you, and that your GP, other carers, and your designated next-of-kin (see below) all have copies. If your family is hostile to your transition, include this information in your instructions, so that your family's wishes will not override yours where there is disagreement. This is especially important to protect you, in case you develop dementia and are no longer able to speak for yourself. See the document "[I'm still me](#)".

Details should include: how you wish to be dressed, including any prostheses, for instance: trans women may need wigs or head-covering, see: www.headwear4hairloss.co.uk; trans men may need breast binders and packers; names, pronouns, titles (Mr, Mrs, Miss, Ms or Mx) should be as you request, except that the death certificate will carry your old name if you do not have a gender recognition certificate. These details should be passed on to the coroner, mortuary staff, and the person conducting your funeral.

Next of kin, nearest relative, power of attorney: If you are married or in a civil partnership, that person will probably be regarded as your next-of-kin, or you can appoint someone to be your next-of-kin. If nobody is acting in this role, care-providers might ask a sibling or child, for instance, to act as your 'nearest relative' in situations where you are unable to make decisions. If you would not be comfortable with that, you can, in addition, give a chosen person 'lasting power-of-attorney' to ensure that your personal wishes are upheld. For more detailed information, see:

► [Bereavement: A guide for Transsexual, Transgender people and their loved ones](#)

Euthanasia and Assisted Suicide

Are you a General Practitioner, current practitioner, locum or retired?

Tell us your views about these end-of-life choices

We are interested to hear how General Practitioners in North Wales engage with the debate around euthanasia and assisted suicide. The voice of this group is rarely heard or reported in the current discussions. The study will be carried out via interviews that will last around 30-45 minutes.

If you want more information about the study, please contact Emily Maddock by e-mail: psp4f4@bangor.ac.uk

*This study has been approved by
Bangor University Ethics Committee and BCUHB R&D department.*

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

Research Project Information Sheet

Project Title: General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

Researcher:

Emily Maddock, Trainee Clinical Psychologist, Betsi Cadwaladr University Health Board. Email: psp4f4@bangor.ac.uk

Supervisor:

Dr Carolien Lamers (project supervisor), Clinical Psychologist, North Wales Clinical Psychology Programme. Email: c.lamers@bangor.ac.uk

Invitation to participate

We are interested to hear how General Practitioners in the UK engage with the debate around euthanasia and assisted suicide. This is a follow up study to the engagement of older people in euthanasia and assisted suicide debate and will use the same methodology, the study will be carried out via interviews.

This information sheet describes the process of the research project, please read it carefully. If there are any issues that are unclear or if you feel that you need more information about the project, please contact Emily Maddock on the contact number or via e-mail at the end of this information sheet. Emily will be happy to provide you with more information and an opportunity to discuss the project. Please do take your time to decide whether you wish to take part in the project.

Purpose of the research project

The debate in the UK is ongoing regarding euthanasia and assisted suicide, however, limited research has been carried out specifically with General Practitioners in the UK. Some studies have been carried out with people suffering a physical illness, health care professionals and the general population. Therefore, we are interested in hearing the voice of General Practitioners in the UK and want to understand how they position themselves in this debate. Your views might shed further light on aspects important in this challenging topic.

Who can take part in the research?

We are looking for General Practitioners working for BCUHB in North Wales to take part in this project.

Regrettably, the researcher is not a welsh speaker and therefore interviews will need to be conducted through the medium of English.

Do I have to take part in the research?

It is up to you to decide whether you wish to take part in the project. If you decide to take part and change your mind, you can withdraw at any point, without giving a reason. All information you have provided up to that point will be removed and destroyed.

What will happen if I do decide to take part?

If you do decide to take part:

1. Please complete the attached consent form and return this by e-mail to Emily Maddock (psp4f4@bangor.ac.uk). You will be asked to sign the form at the time of the interview.
2. You will be contacted by Emily to arrange a convenient time and place for an interview. This can either take place at Bangor University, your local surgery or another location. Any costs that you incur for traveling will be reimbursed.
3. The interview is likely to take between 30 and 45 minutes, you will be asked to provide general demographic information.
4. The interview will be recorded.

What are the potential risks in taking part in the research?

We do not anticipate any risks in taking part in the project. However, euthanasia and assisted suicide are emotive topics and the interview could remind you of experiences that are related to death and dying. You can of course end the interview at any time without giving an explanation. If you feel that you would like further advice and support, information about relevant agencies can be discussed with you.

All information that you provide will be strictly confidential. However, if you share information that might cause concern to the interviewer, Emily will discuss this with you and if required relevant organisations and bodies will be informed. Emily will be adhering to strict confidentiality rules, and will transcribe the interview. Any paperwork and recordings will be kept in a locked cabinet at the University and the transcripts on a password protected laptop. The interview will be wiped of the recorder and the laptop, and any paperwork destroyed, in line with data

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protection legislation and Bangor University policies. Your interview will be used in the write up of the project but you will not be named and any identifying factors will be anonymized.

What will happen to the results of the research project?

When the project is completed, a written summary will be sent to everyone who took part and who indicated on the consent form that they would like feedback regarding the project. As this project forms part of a doctorate qualification, a copy of the project will be kept at Bangor University. The project may be published and presented at different conferences. Again, you will not be identifiable in any way.

Who has reviewed the research project?

This research has been reviewed and approved by the Ethics Committee of the School of Psychology, Bangor University and the local Betsi Cadwaladr University Health Board Research and Development department.

Contact details for further information about the research project:

Emily Maddock
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
Rhaglen Seicoleg Clinigol Gogledd Cymru
School of Psychology – Ysgol Seicoleg
Bangor University – Prifysgol Bangor
Brigantia
Gwynedd
LL57 2AS

Email: psp4f4@bangor.ac.uk

If you have any complaints about how this study is conducted, please address these to the person below:

Hefin Francis
School administrator
School of Psychology
Bangor University,
Adeilad Brigantia,
Penrallt Road,
Bangor, Gwynedd, LL57 2AS
h.francis@bangor.ac.uk

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**Thank you very much for taking the time to read this information sheet and
for considering taking part in the research.**

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Research Informed Consent Form

Project Title: General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

Researcher: Emily Maddock, Trainee Clinical Psychologist, Betsi Cadwaladr University Health Board. Email: psp4f4@bangor.ac.uk

Please read the following statements and, if you agree, initial the corresponding box to confirm agreement:

	Initials
I confirm that I have read and understand the information sheet for the above research project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="text"/>
I understand that my participation is <u>voluntary</u> and that I am free to withdraw at any time without giving any reason.	<input type="text"/>
I understand that the interview will be recorded and transcribed. All identifiable information about me will be removed.	<input type="text"/>
I understand that my data will be treated confidentially and any publication resulting from this work will report only data that does not identify me.	<input type="text"/>
I understand that disclosure of practice that might cause concern to the interviewer will be discussed with me and relevant organisations and bodies will be informed if required.	<input type="text"/>
I agree to participate in this study.	<input type="text"/>
I would like to receive a summary of the research project.	<input type="text"/>

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Signatures:

_____ Name of participant (block capitals)	_____ Date	_____ Signature
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_____ Researcher (block capitals)	_____ Date	_____ Signature
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If you would like a copy of this consent form to keep, please ask the researcher.

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Interview Schedule

<p>1. Externalising: to establish the knowledge and understanding of the term used</p> <p>a) Can you tell me in your words what euthanasia means? b) can you tell me in your words what assisted suicide means? c) How are they the same, different?</p>
<p>2. Personalising: to access the language used by the participant to ascertain development of ideas and personal meaning</p> <p>a) What does euthanasia/assisted suicide mean to you as a practitioner? b) What does euthanasia/assisted suicide mean to you as a person? c) When did you first start thinking about euthanasia/assisted suicide? d) How have your ideas developed over time, what has influenced your thinking? e) How do you feel about legalising euthanasia/assisted suicide?</p>
<p>3. Specifying: circumstances under which they would consider euthanasia/assisted suicide</p> <p>a) How/what does life need to be like, for you to consider EU/PAS as a potential option? b) Under what circumstances would you consider EU/PAS as acceptable? d) How you this be different for/in case of depending on the nature of the conversation?</p>
<p>4. Closing questions:</p> <p>a) Is there anything that we have not discussed that you feel is relevant? b) Are there any areas that you feel are just too difficult to discuss?</p>

	Transcript interview with Grace	Themes and discourses	Language, omissions, differences, alternatives	Foucauldian concepts	Inter-relationships between discourses	Effects of discourse
EM	Can you tell me in your own words what euthanasia means?					
GP	Euthanasia is (..) I think, inducing death in another when death is not going to be erm (..) the next natural step, so it's an intervention in order to end someone's life.	Death – natural EU – treatment	Inducing Intervention	Knowledge		
EM	And again in your own words, what assisted suicide means?					
GP	For me assisted suicide is when someone has made the choice that they wish to end their life but doesn't have the means to do it without someone else to help them. And therefore requires assistance either to acquire the means or actually to go through with the process.	Rights – AS – help	 process	Knowledge		
EM	How would you say they are the same or different or (..)					
GP	I suppose they are slightly different in that assisted suicide suggests that this person is making the plans and simply requires help with the actual process of doing , whereas euthanasia would suggest that others have more of a say in the initiation and carrying out of the act. That for me is the difference.	Rights – choice Responsibility		Knowledge		
EM	And in a 'practitioner mind set', what would you say euthanasia and or assisted means to you?					

GP	<p>Hmm, my views as a practitioner I suppose have changed over the years in that when I was a nice new rookie I would probably largely have been against it. Now, I think I feel that I don't have the right to impose what I would choose for myself on others. We give choice in medicine on so many issues, we involve people in choice more. And therefore my view now is that people probably have the right to choose for themselves whether or not their life should be ended.</p>	Rights	End vs. killed	<p>New knowledge – changes discourse</p> <p>Expert position</p>		
EM	So would you say you feel it's something that people should have access to?	rights		Power – should		
GP	I do feel it's something that people should have access to, yes.					
EM	And what would it mean to you personally? Not as a GP, it may be the same thing or maybe there is a difference?					
GP	<p>I think that as a person, because I haven't had to face (.) the concept of assisted suicide for myself, that's difficult (..) I haven't had to face it so I don't really know how I would react. So I'm hedging my bets on that one but I would not rule it out. Therefore I think I have to say I am in favour of having that choice. It is better to have the choice and not to exercise the choice to take one's life than not to have the choice at all.</p> <p>And for people who are able bodied they do have a choice as to whether to end their</p>	<p>EU/AS – uncertainty, availability</p> <p>Rights – choice</p> <p>Rights – choice Illness</p>		<p>Knowledge</p> <p>Power</p>		

	lives, it's just that some people find themselves in the situation where they are unable either to make that decision or to actually take the action. And therefore I don't know why their rights should be less than the rights of anybody else who is able to take their own life.	Rights				
EM	When would you say you first started thinking about euthanasia, aware of it or just thinking about it?					
GP	<p>Certainly as a very young doctor (.) in the days when (.) I was well aware that patients who were dying would have their medication increased daily (.) to keep them comfortable. Which I think was our very kind way of achieving possibly what people want to achieve now. But it wasn't looked at and it wasn't regulated and it put us all in a very difficult position.</p> <p>I was seeing that going on that made me think we are in a very vulnerable position here and it would be better if as a society we were able to talk about death and the need to insure that people had good deaths than we were.</p> <p>I went to a wonderful talk by xxxxxxxxxx when I was a medical student who was a Russian orthodox priest. Who talked about death and our experiences of death and about demystifying it and that was a really seminal point in my life when I started to</p>	<p>Medical – helping</p> <p>Covert GP's in difficult position</p> <p>GP in difficult position</p> <p>Death – taboo</p> <p>Death – good death</p> <p>Death - taboo</p>		<p>Surveillance Reduced power</p> <p>Power</p> <p>Knowledge</p> <p>Knowledge</p>	Legal	<p>Challenge existing discourse</p>

	think about the whole subject and not just pushing it to the side. It was very important in formulating my views about it.		'it'	object		
EM	It is interesting isn't it that as a society how that changes over time (.) years ago maybe lots of people died at home with people around them (.) maybe not so much now?					
GP	<p>It isn't, it's very (.) and the less rituals surrounding it. One of the things that he said is that we are one of the very few societies who cover our dead. So we just don't want to look at it. And that we don't any longer have that ritual mourning that you would have in some middle eastern countries which give those are bereaved to move on at a sensible pace. We just push it out of the way and after 6 weeks you are supposed to be better.</p> <p>I thought about death a lot as a medical student and then once I qualified I realised that erm (.) we tried always to be kind to our patients to comfort our patients and that might involve helping then towards a death that would occur slightly sooner but more comfortably. But this was an unregulated activity that put doctors and nurses and health care professionals in a very vulnerable position.</p>	<p>Death – taboo</p> <p>Medical - GPs as kind, good</p> <p>covert</p> <p>GPs as vulnerable</p>		<p>Knowledge</p> <p>Power</p>	<p>Legal</p>	
EM	We touched on this a bit but how would you say your views and ideas have developed over time?					

GP	<p>I think they developed in terms of having more experience of different diseases. When I qualified, dementia wasn't the enormous problem that it is now because more of our patients didn't live long enough to become demented. A 90 year old was a rarity whereas now I could sit through a surgery where most of my patients are over 90. And therefore the incidence of dementia has risen and that in its self brings huge problems in terms of people not being able to choose when they have capacity what will happen to them when they don't.</p> <p>My own father died of dementia and bless him, we often used to say dad had survived about 5 years beyond his sell by date. And that was said in a kind way because it was a very very very cruel experience.</p>	<p>Illness – as a problem</p> <p>Aging</p> <p>Rights – choice, planning ahead</p> <p>Illness – cruel</p>	Humour	<p>knowledge object</p> <p>subject</p> <p>power</p>		
EM	And there is that point from a medical stance about prolonging life and at what point (.)					
GP	Absolutely, and as society becomes less comfortable with the concept of death and wants to keep people as long as possible and we are not supposed to be age discriminatory, the care that we're now offering people is probably worse than it was many years ago when we were rather more pragmatic about not treating chest infection or other things.	<p>Death</p> <p>Ageing</p> <p>Medical</p>		<p>Society - power</p> <p>subject</p>		

EM	And would you say there are any particular experience that really changed your views or stood out for you?					
GP	It was partly over time but on several occasions over my career I have had people ask that I should end their lives (..) and you know I've always had to say (..) erm, I can't do that, what I can do for you is that I can make sure that you don't suffer and I can help to relieve your pain and in doing that that may shorten your life a little but I cannot do what you want me to do <i>now</i> which is to choose a time when you will end your life. You know that's not within my remit as a doctor. And I have had patients that have gone to Dignitas (..) erm, and I've had patient who have asked about that. But I suppose it is, over the years you have this recurring pattern of people feeling that they have reached the point of no return for them.	EU/AS – taboo Legal palliative Medical – relieving Rights – choice EU/AS – as an option, taboo		Power expert Power subject Power		Challenge to existing discourse Shut down discourse Challenge to existing discourse
EM	Do you feel that you were able to have that open dialog around those issues					
GP	yes	EU/AS - taboo				Challenge to existing discourse
EM	And patients were able to ask those questions?					
GP	Yes, I never approached it, it would always be a case of waiting for the question to arise. I think there has been many a conversation with relatives along the lines of it would be kinder not to intervene here	EU/AS – taboo		Knowledge Power Subject - patient		

	than to carry on treating, which is slightly different but I think it's only one angle of the same thing. So yes I've been very proactive in suggesting that we are not doing a service for someone by simply just trying to keep them alive at any cost. But equally I am very aware of the fact that I have never raised to concept that someone might want to end their life. That always come from the patient.	EU/AS as kind Death – as relief		Expert - GP Power		
EM	I'm just curious about those people that have gone outside of the UK, was that something that was (.) a very difficult situation, because the availability wasn't here? How did you feel about it?					
GP	I suppose like many people I watched the television programme about Dignitas and about the process and found it quite a soulless experience. If we are going to allow people to take their own life or to opt to have someone else end their life... surely we should be able to allow them to choose the circumstance in which that happens. You know people spend so much effort planning their weddings and everything else. Surely if you are going to plan your own death you should be able to do so in a situation where you can be in a comfortable setting surrounded by your loved ones, or by no one if that's what you choose to do. You should have some	EU/AS – access Rights – choice Death – a good death	Allow – power	Power with GP Power		

	<p>control and choice about the circumstances (.) that was important for me.</p> <p>I think (..) it caused, in the couple of experiences that I had where people wanted to go to Dignitas and one did, it was quite <i>sad</i> really for the family (..) because it must be horrible to have to go abroad and then find yourself without that loved one coming back. You know, it's analogous in a way, I always used to find, I worked in a kidney transplant unit and I hated the moment when we took donors to theatre to retrieve the organs and after the organs had been retrieved (..) they turned off the ventilator that was giving oxygen. So you went from the noise of the ventilator in theatre which was very normal to silence (..) and there was an enormous void between that noise, the sounds, the normality (..) and the fact that we now had someone who was dead. Even though I knew they were brain dead before, and apparently now they don't do that, they keep the, keep it going. Because obviously I wasn't the only one who found this a very strange experience. It must be terrible for relatives to have to go with someone to Switzerland and then (..) come back without that person, without having their community around them to support them.</p>	<p>Rights – choice</p> <p>Death – loss EU/AS – availability positive Rights</p> <p>Medical</p> <p>Death – difficult</p> <p>Loss</p>	<p>'we took'</p>	<p>Power</p> <p>Power – expert</p> <p>Object</p>		
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	How do you repatriate the body? I have no idea (.) just the sheer practicalities, you can't just phone your local undertaker and say could you drive out to Switzerland and pick auntie Jo up. You know, I think that is hugely problematic and we should do better than that for people.	EU/AS – UK access Rights – choice GP as caring				
EM	How do you feel about legalising euthanasia and assisted suicide in the UK?					
GP	I think it should be legalised, I think we just have to be grown up now.	EU/AS – good				
EM	Do you have any views around if that were to happen what you would want it to look like or how it should look?					
GP	I don't think the Swiss model is a bad one that it is not doctors administering the (.) treatment. I actually think there is an important distinction between doctors supporting euthanasia and assisted suicide and being the agents there of. Erm, I suppose it could work if you had the equivalent that we have in termination clinics. Where you have doctors who simply work there (.) or nurses who work there. Erm, equally, (.) in terminations you know, doctors have the right to opt out, but it can be made quite difficult for them to opt out. I think it's really really important that the process is only carried out by those people who are very comfortable that this is a service they want to provide. Erm, and I'm not sure that that should necessarily be doctors or whether it should be	Responsibility – not GPs Someone else should do it Rights – GP choice Rights – choice	'simply work there'	Power expert object Power		

	practitioners who are simply there to administer the means. So you know, it shouldn't be impossible to devise a system erm, (.) but obviously with the system we have in the UK you need a doctor to prescribe drugs. I think a lot of people would be (.) probably happy to do that but not happy to actually hand it over. And I certainly would not want to be the person doing that. I'm not even sure that I would want to be the person writing the prescription. But I think that's probably because I'm a coward and I haven't quite got that far down the journey.	EU/AS as possible Responsibility – Bravery?		Objectification expert		
EM	It's interesting, other people have said very similar things (.)					
GP	Mmm,					
EM	If it were legalised, how and who would be doing what and how would that look and where do GPs sit within that (.)					
GP	I think it is very difficult for GPs who are practicing within a community maybe for 30 years (.) erm, you know, it's not great to have a reputation as the one who will bump you off if you get a bit too problematic. So I think actually having a system that's slightly more remote than that would be quite important.	EU/AS – as negative, reputation	Bump you off	Knowledge object power		
EM	So having a system where GPs role might be to have the initial conversation and make the referral?					
GP	I think so, and to refer in, and then you can have a system set up where you can have	Someone else should do it		GP – expert power		

	<p>independent assessment of peoples capacity, looking at their choices and looking at safeguarding to ensure that there isn't pressing being put, and I think GPs would have a big role in any knowledge they have of the family that might help that decision but (.) the actual process of going about it, I think that's probably a bridge too far for most GPs or certainly would be for myself and my practice.</p> <p>You know, we refer for terminations but we wouldn't all be prepared to do terminations. And in fact I was in exactly that position, I didn't do, I didn't carry out terminations but I would refer people because I respected their right to make that choice.</p>	<p>Illness – capacity</p> <p>Moral/legal</p> <p>choice</p> <p>Responsibility – bravery?</p> <p>Rights – GP choice</p> <p>Rights - choice</p>		<p>Knowledge</p> <p>expert</p> <p>Power</p>		Using existing discourse
EM	Would you have any concerns about the legalisation or for GPs within that?					
GP	<p>No, I think if you devise a system, which is a thorough system, you're never gonna get it right all the time but we don't get it right all the time now, erm (.) if parliament, the law is behind the system that we choose to implement then I don't think that should be a huge concern for GPs. Other than their own personal views on whether or not this is a process in which they wish to participate. And I guess the GMC in the event of it being legalised would go down the road that they have gone with termination which is you don't have to</p>	<p>Medical – limited</p> <p>Legal</p> <p>choice</p> <p>Rights- GP choice</p>		<p>Surveillance</p> <p>Power</p> <p>Knowledge</p> <p>Surveillance</p>		

	provide the service but what you have to do is tell people who they can go to to access the service.	Responsibility – GPs			Legal	
EM	And from that practitioner perspective, what would you say life would need to look like or be like for you to consider that euthanasia or assisted suicide was either an option or appropriate?					
GP	I'm not sure that it's got anything much to do with the practitioner (..) certainly not for assisted suicide because that has to be something that is raised by the person who is ill. With euthanasia it's more difficult. And I suppose (..) you would then be looking at you know, at the moment it's kind of by the back door by let's put in DNR orders on people, well what are we really saying in that situation? You know, in the event of something happening we are not actually going to give you active care, well that's one step along the road to actually having that conversation with relatives which would be (..) I really do think we are reaching the point where quality of life is really dreadful here and we now say to them I think it would be counterproductive in the event of something happening to try to resuscitate this person, if their heart stopped or whatever. Maybe we would need to be more brave and say, you know do you feel that we should be looking at the option of ending this person's life. I don't think it's a massive step because if we	<p>EU/AS – choice</p> <p>Covert</p> <p>Illness- QOL</p> <p>Bravery?</p>	'put in'	<p>Patient - object</p> <p>GP - expert Patient - subject</p> <p>power</p> <p>Knowledge</p>		

	really looked inside what we are doing we are probably not that far away now.	EU/AS – taboo				Challenge dominant discourse
EM	And would there be certain circumstance where you would feel more comfortable with that than others?					
GP	Yes.					
EM	Very very close to the end Vs. weeks and weeks away?					
GP	<p>I think for assisted suicide I think people have the right, if they have capacity they have the right to make their decisions, if they're not mentally ill, if they're not psychotic, they have the right to choose just as everybody else does.</p> <p>I had a very good friend who took her own life (..) she had multiple sclerosis and she chose to walk into a lake, she couldn't swim. But she chose to walk into a lake when she could still walk. Now she probably had a lot of years ahead of her but she was well aware of the fact that she wouldn't be able to make that choice later on. Which is very sad. Erm, I think it is much more difficult when you are talking about euthanasia and (..) erm, I think you would have to, we would have to devise some sort of system of assessing quality of life in a better way than we do. Erm, but certainly somebody who is having repeated treatments that become more ineffective each time we give them, somebody who's</p>	<p>Rights – choice</p> <p>Illness – physical vs. mental</p> <p>Rights – choice</p> <p>EU/AS – uncertainty</p> <p>Medical – limited</p>		<p>Power</p> <p>Expert – GP</p> <p>Knowledge – medical</p>	Moral?	

	dementia is progressing relentlessly and causing enormous distress to them (.) never mind to their families. And it should be about the patient not really about the family. Erm (.) so I think you would have to be a long way down the road towards death or appalling suffering to suggest euthanasia, with assisted suicide I think it's up to the individual. At what point they choose. Just as they would if they could walk to Boots, buy 200 paracetamol and swallow them.	Illness – distressing Rights – choice Death – imminence Rights – choice				
EM	And for you personally, what would life have to look like? Would that be any different? Do you have different feelings about it personally from if it was a patient?					
GP	Erm, I don't think it's much different, having seen my father die of dementia I would like to be able to, if I was dementing, I would like to be able to make the decision when I still had capacity, that you know... to lay down criteria, that if I was no longer meeting those criteria I would be happy for someone to terminate my life. And that I was taking that decision rather than putting that burden on my family because I think the burden on the family at that point is truly intolerable. I went to an EMI unit last summer on a terribly hot day and it was like entering bedlam. It was truly truly appalling and I really felt that the quality of care I was	Rights – planning ahead Burden Medical – limited		Power Knowledge - expert		

	<p>giving, by giving people antibiotics and by giving people supplementary oxygen was just so awful. You know (.) I think that tells me that I don't want to get to that stage, I really don't want to go there thank you very much, I really hope that by the time I'm there we might have changed the law.</p> <p>So I think you have to be a very long way down the road but perhaps the decision to intervene has to be taken when you are not so far down the road that you can't make the decision. And I think that's what's so awful at the moment, that people with perhaps multiple sclerosis know where they are going but the cant make those plans.</p>	<p>EU/AS – personal</p> <p>Legal</p> <p>Death – imminence</p> <p>Rights</p>		<p>Knowledge, power</p> <p>Power</p>		
EM	Thank you, is there anything, any other views or anything relevant that we haven't covered that you would like to share or discuss?					
GP	Just one thing is that we are looking at the issue from the point of general practice, I also worked in a hospice for many years erm, and I think there's (.) there are views on both sides in the hospice movement about assisted suicide and euthanasia and you know, Barrenness Finley is very vocal in her opposition to the law being changed and so on, so I think there's going to (.) it would be very interesting to look at the views of people in the palliative care	<p>Legal</p>		<p>Knowledge - expert</p>		

	<p>movement because one of the things that working in palliative care taught me is that you can't always palliate. And if I had my career again I might actually do palliative care rather than general practice or I might carry on doing the two in parallel. Because it's a branch of medicine that I loved doing, I really enjoyed, I had some of my best times working as a doctor with people who were terminally ill. But I think an honest discussion has to be had within that movement as to whether euthanasia or assisted suicide should be part of the package of palliative care that is offered to all.</p>	<p>Medical – limited</p> <p>EU/AS – useful</p>				<p>Challenge to dominant discourse</p>
EM	<p>Do you think the advances in medicine have changed palliative care and how end of life can be managed?</p>					
GP	<p>I think end of life can be managed in most people very well. But (.) there's a very significant minority that nobody wants to talk about where you fail miserably to control the most awful symptoms. Erm, and that is (.) very recently someone who is a family friend has died a totally miserable death from bowel cancer. And I was talking to another friend who is a nurse, who nursed this man in his final days and we were discussing the fact that when as a spouse you have nursed someone through such a horrendous experience, life can never return to the same (..) quality that it</p>	<p>Medicine – effective, good</p> <p>Medical – limited</p> <p>Death –miserable</p> <p>Illness/death – horrendous, traumatic</p>		<p>Power GP - subject</p>		

	<p>was before. Not because you have lost your loved one but because you have seen a human being that you love so deeply suffer so dreadfully badly. And been powerless. And I think perhaps that's the crux of the argument, it is the fact that at the moment the state has the power and not the individual. And yet we, we are supposed to give people all the options when they go for an operation and tell them all the complication that could arise and at all points we are supposed to give choice. You know, negotiate whether you are going to have antibiotic, whether you are going to have physiotherapy or whatever. But we are not brave enough to address the fact that people should have choice about whether their lives continue or not. And the one other thing that has really perhaps cemented my views is that Desmond Tutu has supported the concept of euthanasia and assisted suicide. And I think for someone like that to make that enormous step forward and to be open and honest is just hugely important for the whole movement. He is one of my heroes. And I think he has been, as he has been throughout his life extremely brave in raising this.</p>	<p>Rights</p> <p>Rights – choice, information</p> <p>Bravery rights</p> <p>EU/AS – supported</p> <p>Bravery</p>		<p>Power</p> <p>power</p> <p>surveillance</p>	<p>Legal</p>	
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