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Supportive and Palliative Care Research in the UK:

Report of the NCRI Strategic Planning Group on Supportive & Palliative Care

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Supportive and Palliative Care Research in the UK:

Report of the NCRI Strategic Planning Group on Supportive & Palliative Care



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1 Executive Summary

- 1.1 The NCRI Strategic Analysis published in October 2002 revealed that research spend on supportive and palliative care was, at most, £11m per annum, which represented about 4.3% of direct research spend by NCRI Partners on cancer research.
- 1.2 In response to this, the NCRI established a Strategic Planning Group (SPG) to examine the past and present state of UK research in this field and to make recommendations to the NCRI Board on strategic actions that could be undertaken to enhance research in this field.
- 1.3 The scope for this work was kept deliberately broad. It encompassed research into all aspects of quality of life and quality of care for cancer patients, their families and carers. The whole care pathway from diagnosis to death (and into bereavement) was considered. Topic areas considered were based on the themes identified in the [National Institute for Clinical Excellence \(NICE\) Service Guidance on Improving Supportive and Palliative Care for Adults with Cancer](#).
- 1.4 The SPG comprised representatives of the key funders of research in this field (Cancer Research UK, Department of Health, Medical Research Council, Marie Curie Cancer Care, and Macmillan Cancer Relief) plus a patient representative.
- 1.5 The SPG assessed:
- o Evidence related to research outputs (papers published) based on an independently conducted bibliometric analysis;
 - o Ongoing research, based on a detailed analysis of the NCRI Cancer Research Database;
 - o The current research workforce, based on a questionnaire survey;
 - o The views of researchers themselves, based on a consultation questionnaire and oral evidence sessions with groups of researchers.
- 1.6 The SPG endorses the views of researchers in supportive and palliative care that this is an important field of research in terms of the potential benefits to patients, carers and health professionals and that there are multiple opportunities for high quality research.
- 1.7 The systematic evidence reviews undertaken for the development of the NICE Guidance revealed strengths and weaknesses in the worldwide evidence base related to supportive and palliative care. Research into patients' needs has been quite strong, whereas research into how best to meet those needs is weaker. Research into psychological support, specialist palliative care, information giving, and face-to-face communication has been an area of success. In contrast, relatively little research has been conducted in relation to: complementary therapies; user involvement; spiritual support; support for families and carers; bereavement support; coordination and integration of care; general palliative care; social care; rehabilitation; cultural differences; under served groups; care sites/settings; and symptoms other than pain.
- 1.8 The worldwide output of research into supportive and palliative care has increased considerably over the past decade, starting from a low base, and has increased more rapidly than that for cancer research in general or for biomedicine as a whole.
- 1.9 Over a nine-year period the research output from the UK was second only to that from the USA. However, research output per head of population in the UK is smaller than that of several other countries (e.g. Sweden, Norway, the Netherlands and Canada).
- 1.10 One third of the research output from the UK came from London, around 8% from Manchester and around 5% from Edinburgh and Birmingham. Eight further cities contributed between 3% and 5% of the output.
- 1.11 Our research mapping questionnaire survey identified a total of 330 researchers, including PhD students, active in this area (around 240 whole time equivalents). These researchers were distributed across 43 groups/locations. Only three groups had more than 20 staff, with a further six groups having between 10 and 19 staff. These nine groups accounted for over half of the research workforce. At the other end of the spectrum over half of the groups (n = 22)

had less than five personnel.

1.12 A wide range of professions contributed to the research workforce including nurses (34%), psychologists (27%), doctors (21%) and sociologists (6%). The medically qualified researchers came from a variety of different disciplines. Around half were specialists in palliative medicine, with general practitioners, psychiatrists, oncologists and public health physicians contributing smaller numbers.

1.13 Around one half of the research groups tended to be isolated from the clinical world. The others were either based in primary care or in hospices.

1.14 Four of the nine groups with ten or more research staff were led by nurses, three by psychiatrists or psychologists, one by a health services researcher and one by a specialist in palliative medicine (figures include PhD students). Research groups led by specialists in palliative medicine tended to be small (less than five personnel).

1.15 The SPG recognised the challenges associated with research in this area. These can be summarised as follows:

o **Organisational issues:**

The research workforce is fragmented across multiple sites, with relatively little interdisciplinary working within supportive and palliative care and relatively little collaboration with researchers outside the field of cancer.

o **Workforce issues:**

PhD training provision is good. However, there are inadequate numbers of postdoctoral fellows and senior lecturers to provide the future leaders in the field. This is largely due to a lack of funded posts at these levels. Researchers with combined clinical and academic posts face serious difficulties in relation to pressures from service commitments. In contrast, some researchers (especially nurses) work in units that are isolated from the clinical world, which also causes difficulties. There is a lack of MSc research training in 'supportive and palliative care'.

o **Infrastructure support:**

Few of the research groups have access to dedicated statisticians and methodologists

who have appropriate expertise in this field. Resources for data management and administrative support are also scarce.

o **Funding issues:**

There is a perceived lack of 'value' placed on health services research generally by the Research Assessment Exercise, with consequent impact on funding from the Higher Education Funding Councils. This occurs despite the high output (and quality) of research in supportive and palliative care in this country, demonstrated by the bibliometric analysis conducted for the Strategic Planning Group. The withdrawal of regional NHS R&D response-mode funding has also caused difficulties.

o **Clinical issues:**

The difficulties in conducting research involving seriously ill patients with limited life expectancy needs to be recognised. Attrition of patients in clinical trials, and missing data, are particular issues within palliative care.

o **Methodological issues:**

In addition to the clinical issues mentioned above, there is a lack of agreement over appropriate approaches to the measurement of outcomes for specific aspects of supportive and palliative care research. Another issue involves the difficulties around the evaluation of interventions in this area, which are often "complex" in nature.

o **User involvement:**

Historically the involvement of service users in research has not been strong.

1.16 To address these challenges, the Strategic Planning Group recommends that the following actions should be taken:

o **Organisation of research:**

The fragmentation of research in this field is already being addressed in part through the establishment of NCRI Clinical Studies Groups on: Palliative Care; Psychosocial Oncology; Primary Care; and Complementary Therapies. In addition to this, consideration should be given to the establishment of interdisciplinary NCRI Supportive and Palliative Care Research Collaboratives, building on the experience of the NCRI

- Prostate Cancer Research Collaboratives.
- o **Workforce issues:**
NCRI Partners should be encouraged to establish postdoctoral and senior lecturer posts, linked to the NCRI Research Collaboratives where possible.
 - o **Infrastructure support:**
NCRI Partners should be encouraged to fund posts for statisticians, methodologists, and data managers, linked to NCRI Research Collaboratives where possible.
 - o **Funding issues:**
The NCRI Board should be asked to make representations to the Higher Education Funding Council for England (HEFCE) (and equivalent bodies for other parts of the UK) regarding the value placed on health services research in general and on supportive and palliative care research in particular.
 - o **Methodological issues:**
Workshops should be convened to address methodological issues and, in particular, to define appropriate outcome measures for different aspects of research in this field. Use of the Medical Research Council (MRC) Framework for Evaluating Complex Interventions is encouraged. The involvement of service users in all stages of research is also encouraged.
 - o **Targeted funding:**
Targeted funding may be needed to stimulate research into themes that are inadequately researched at present.

2 Introduction

2.1 In October 2002 the NCRI published its report 'Strategic Analysis 2002: An Overview of Cancer Research in the UK directly funded by the NCRI Partner Organisations' (www.ncri.org.uk). This report revealed, amongst other things, that research spend on supportive and palliative care was low compared with other areas (details in Section 5). The NCRI therefore established a Strategic Planning Group (SPG) to examine the situation in more detail.

- 2.2 The remit of the SPG was to
- examine the past and present state of UK research in the field of supportive and palliative care for Cancer,
 - identify needs and opportunities for the future,
 - clarify specific issues and barriers,
 - develop proposals for national strategic actions (e.g. structures, training, workforce, and funding).

Membership consisted of representatives from research funders, plus a patient representative (details at Appendix 1).

2.3 Evidence was obtained from a number of sources as follows:

- An analysis of research outputs in the form of a bibliometric study of publications (1994 - 2002) commissioned from the School of Informatics at City University, London (details in Section 4):
- An examination of current/ongoing research in the form of a detailed analysis of the NCRI Cancer Research Database (details in Section 5);
- An analysis of research workforce capacity, and stakeholder views, in the form of a questionnaire survey (detailed in Section 7 and Appendix 2);
- Oral evidence sessions with groups of researchers (details at Appendix 1);
- The report of a patient consultation exercise undertaken by Macmillan Cancer Relief ('Workshop to seek the views of people affected by cancer on priorities for research in cancer care')

2.4 The SPG met eight times as a group from January 2003 to May 2004.

3 Scope: What is Meant by Supportive and Palliative Care?

- 3.1 The scope of the work undertaken by the Strategic Planning Group (SPG) was deliberately kept broad. It encompassed:
- Research into all aspects of quality of life and quality of care for patients, their families and carers.
 - The whole care pathway from diagnosis to death (and into bereavement for carers).
 - The impact of caring for cancer patients on the well-being of health professionals.
 - Research into the education and training of health professionals delivering supportive and palliative care.
 - Assessment of patients' and carers' needs.
 - Assessment of the quality of supportive and palliative care services.
 - Evaluation of new interventions and service models.

- 3.2 Specific topic areas considered by the SPG were based on the themes of the [NICE Service Guidance on Improving Supportive and Palliative Care for Adults with Cancer](#). These are:
- Co-ordination of care
 - User involvement in planning, delivering and evaluating services
 - Face-to-face communication
 - Information
 - Psychological support services
 - Social support services
 - Spiritual support services
 - General palliative care services
 - Specialist palliative care services
 - Rehabilitation services
 - Complementary therapy services
 - Services for families and carers, including bereavement care

4 Research Output from the UK 1994 - 2002

- 4.1 The NCRI Secretariat commissioned a study of research outputs (publications) from Professor Grant Lewison at the School of Informatics, City University, London. The study was carried out by Isla Rippon.
- 4.2 The study was based on papers retrieved from the Science Citation Index (SCI) and the Social Science Citation Index (SSCI) by means of a special filter (Supportive and Palliative Care - SUPAC) based on paper titles and journals. The filter was developed in consultation with Dr Helen Campbell of the NCRI Secretariat.
- 4.3 The study covered papers published worldwide over a nine-year period (1994 - 2002). Particular emphasis was placed on 18 Organisation for Economic Co-operation and Development (OECD) countries.
- 4.4 The Journals in which articles appeared were graded according to their 'Potential Impact Category' (PIC) from 1 = low to 4 = high; based on mean five-year citation scores), and according to 'Research Level' (RL) from 1 = clinical to 4 = basic. Examples of PIC levels for papers relevant to supportive and palliative care (SUPAC) are as follows:
- 1 Supportive Cancer Care; Psycho-Oncology; Cancer Nursing
 - 2 European Journal of Cancer; Palliative Medicine; Annals of Oncology
 - 3 British Medical Journal; Cancer; British Journal of Cancer
 - 4 Journal of Clinical Oncology; Journal of the American Medical Association; Lancet
- 4.5 Papers were ascribed to geographical locations within the UK according to the first two letters of the postcode.
- 4.6 For the purposes of comparison, comparable analyses were also undertaken of all cancer research articles and all biomedical articles.

World Overview

- 4.7 The average world annual output of SUPAC papers over the nine-year period was 977 (compared with 33,893 papers related to cancer research and 274,742 papers related to biomedicine).

- 4.8 Worldwide output of papers related to SUPAC increased over the nine-year period. The ratio of SUPAC papers published in 2001 - 2002 to those in 1994 - 1995 was 1.72. This was considerably larger than for cancer research generally (1.14) and for biomedicine (1.12).

UK Perspective

- 4.9 In terms of average annual output over the nine-year period, the UK contributed 12% of the world output of SUPAC papers, compared with 8% of cancer research papers and 10% of biomedicine papers.
- 4.10 The UK average annual output of papers over the nine-year period was 113. This places the UK second behind the USA (379) and ahead of Canada (81), Germany (70), Italy (54), the Netherlands (45) and Sweden (43).
- 4.11 When these figures are adjusted for population size (to give average annual output of papers per million population) the rankings change significantly. The UK (at 1.9) moves ahead of the USA (1.3) but moves behind Sweden (4.8), Norway (3.7), the Netherlands (2.8), Switzerland (2.7), Canada (2.6), Finland (2.1), and Denmark (2.0).

Distribution by 'Research Level'

- 4.12 Not surprisingly the large majority of the world output of SUPAC papers (77%) were in journals classified as clinical (RL 1.0 - 1.5) with only 4% being published in journals at the basic research end of the spectrum (RL 3.0 - 4.0).
- 4.13 The UK picture was similar to that for the rest of the world with 73% of papers being published in 'clinical research' journals and 3% being published in 'basic research' journals.

Distribution by 'Potential Impact Category'

- 4.14 A total of 8,789 SUPAC papers published worldwide (1994 - 2002) were assessed for the 'Potential Impact Category' (PIC) of the journal in which they were published. Of

these, 52% were PIC 1 (low); 25% were PIC 2; 17% were PIC 3 and 6% were PIC 4 (high).

- 4.15 A total of 1,021 papers from the UK were assessed for 'Potential Impact Category'. The UK fared well on this indicator with 42% PIC 1 papers; 32% PIC 2; 21% PIC 3 and 5% PIC 4 ($p < 0.01$ compared with the world figures).
- 4.16 In relation to mean PIC factor the UK was ranked third amongst the 18 OECD countries (with a mean PIC level of 1.89). Only the Netherlands (mean 1.97) and the USA (mean 1.96) fared better.

Geographical Distribution

- 4.17 The analyses of postcodes for papers showed that 34% came from London (including Sutton/Cheam), around 8% from Manchester and around 5% each for Edinburgh and Birmingham. Oxford, Cambridge, Liverpool, Leeds, Sheffield and Bristol each contributed between 4 and 5% of the total and Southampton, Cardiff and Nottingham between 3 and 4%.

5 Current Research (and funding) in the UK

- 5.1 In October 2002 the NCRI published its document 'Strategic Analysis 2002: An overview of cancer research in the UK directly funded by the NCRI Partner Organisations'. This overview was based on an analysis of the data held at the time on the NCRI Cancer Research Database (CRD). The CRD is designed to contain accurate information on the directly supported cancer research funded by NCRI Member organisations.
- 5.2 Information on the CRD is in the form of a common data set that includes details of the Principle Investigator(s), an abstract of the research conducted, and details of the funding awarded. Every project is coded using two internationally recognised classification systems:
- o The Common Scientific Outline (CSO)
A classification system of cancer-related research terminology that categorises research activities into specific areas (e.g. Biology, Aetiology, Treatment etc.)
 - o Disease Site codes
- 5.3 The CSO code relevant to supportive and palliative care is CSO code 6 'Cancer Control, Survival and Outcomes Research'. Table 1 shows a full breakdown of CSO code 6. Subdivisions 6.2 and 6.7 ('Surveillance' and 'Ethics and Confidentiality in Cancer Research') were considered outside the scope of supportive and palliative care, as defined, and relevant records were therefore excluded from the analyses.
- 5.4 The total annual spend on supportive and palliative care was £11.04m, which constitutes 4.3% of the total spend on all areas of cancer research. Figure 1 shows that the largest portion of this spend was on 'Resources and Infrastructure Related to Cancer Control, Survival and Outcomes Research' (35%), closely followed by 'Patient Care & Survival Issues' (27%).
- 5.5 The distribution of spend across the UK showed that research groups in London were in receipt of the bulk of funding (28%). Other geographical centres of note included Manchester (14%), Leeds (12%), Oxford (6%), and Edinburgh (5%).
- 5.6 Figure 2 shows that Cancer Research UK was the major funder of research on patient care and survival issues; behaviour related to cancer control; and education and communication (the latter closely followed by Macmillan). The Department of Health (DOH) was the major funder of cost analyses and research into health care delivery; end of life care; complementary and alternative approaches; and resources and infrastructure.
- 5.7 Cancer research can be broadly divided into two modes of study; research that is focused on specific tumour types (Site Specific Research) and research that is generic and may be applied to all types of cancer. Generic research can be further subdivided into two groups; research that is pre-clinical and describes mechanistic studies ranging from regulation of basic biological processes, drug synthesis and metabolism, to the design of diagnostic instruments (Fundamental Research); and more 'patient focused' research that is relevant to all cancer types such as cancer education and communication, novel drug delivery systems in clinical trials and studies relating to pain management (All Sites). The analysis of supportive and palliative care research revealed that 36% of research spend was on Site Specific research; 2% was on Fundamental Research; and 62% was on research that was relevant to All Sites. Figure 3 shows that, of the research that was Site Specific, breast cancer was by far the tumour site receiving the most spend (nearly 35% of the total). Colorectal, prostate, and ovary, each comprised about 10% of the investment.
- 5.8 The nominal supportive & palliative care portion of the DOH investment in the National Cancer Research Network (NCRN) and the National Translational Cancer Research Network (NTRAC) comprised a significant proportion of the total spend. When this was excluded from the analysis a picture of the duration of grants emerged (Figure 4). Grant durations were defined as short (≤ 1 year), medium (1 - 3 years) or long (>3 years). Medium length grants comprised the largest proportion in terms of numbers (49%), but the largest proportion of spend was long-term grants (58%).

Table 1 Breakdown of Cancer Control, Survival & Outcomes Research Category (CSO 6)

6.1-Patient Care and Survivorship Issues

Examples of science that would fit:

- Quality of life.
- Pain management.
- Psychological impacts of cancer survivorship.
- Rehabilitation.
- Reproductive issues.
- Long term morbidity.
- Symptom management, including nausea, vomiting, lymphedema, neuropathies etc.
- Prevention of treatment related toxicities and sequelae including symptom management, prevention of mucosities, prevention of cardiotoxicities, etc.

6.2-Surveillance

Examples of science that would fit:

- Epidemiology and End Results Reporting (e.g., SEER).
- Surveillance of cancer risk factors such as diet, body weight, physical activity, sun exposure, tobacco use.
- Analysis of variations in risk factor exposure by demographic or other factors.
- Registries which track incidence, morbidity and/or mortality related to cancer.
- Trends in use of interventional strategies.
- Method development for risk factor surveillance.

6.3-Behavior

Examples of science that would fit:

- Behaviour medicine research and interventions.
- Influence of social factors, such as: community, policy, education, and legislation on behaviours related to cancer control.
- Attitudes and belief systems and their influence on psychological health and on behaviors related to cancer control. For example, how beliefs can alter attempts to seek screening, detection, and treatment.
- Interventions to change attitudes and beliefs that affect behaviour related to cancer control and cancer outcomes.
- Influences of attitudes and beliefs on compliance to treatment and prevention protocols.
- Psychological or educational interventions to promote behaviours that lessen treatment-related morbidity and promote psychological adjustment to the diagnosis of cancer and to treatment effects.
- Burdens of cancer on family members/caregivers and psychological/behavior issues.

6.4-Cost Analyses and Health Care Delivery

Examples of science that would fit:

- Analyses of cost effectiveness of methods used in cancer prevention, detection, diagnosis, prognosis, treatment, and survivor care/support.
- Development and testing of health service delivery methods.
- Interventions to increase the quality of health care delivery.
- Impact of organisational, social, and cultural factors on access and quality of care.
- Studies of providers, such as geographical or care-setting variations in outcomes.
- Effect of reimbursement and/or insurance on cancer control, outcomes and survivorship support.
- Access to care issues.

6.5-Education and Communication

Examples of science that would fit:

- Development of communication tools and methods.
- Education of patients, health care providers, at-risk populations, and general population about cancer.
- Communication to patients regarding therapeutic options.
- Educational interventions to promote self-care and symptom management.
- Communicating cancer risk to underserved populations, at-risk populations, and the general public.
- Alternative teaching methods to communicate therapeutic options and risk reduction behaviour to patients or the general public.
- Communication of lifestyle models that reduce cancer risk, such as communication of nutrition interventions.
- Communicating smoking and tobacco cessation interventions.
- Special approaches and considerations for underserved and at-risk populations.
- Education, information, prevention/screening/assessment systems for the general public, primary care professionals or policy makers.
- Training, predictive cancer models, pain management, and surveillance systems for primary care professionals, telehealth/telemedicine applications.
- Communication regarding cancer genetics, managed oncology care, communicating with survivors.
- Barriers to successful health communication.

6.6-End-of-Life Care

Examples of science that would fit:

- End-of-life Care issues including palliative care, psychological interventions with families at end of life, hospice care, pain management for terminally ill patients, etc.

6.7-Ethics and Confidentiality in Cancer Research

Examples of science that would fit:

- Informed consent modeling and development.
- Quality of Institutional Review Boards (IRB).
- Protecting patient confidentiality and privacy.
- Research ethics.

6.8-Complementary and Alternative Approaches for Supportive Care of Patients and Survivors

Examples of science that would fit:

- Hypnotherapy, relaxation, transcendental meditation, imagery, spiritual healing, massage, biofeedback, etc., as used for the supportive care of patients and survivors.
- Discovery, development and testing of complementary/alternative approaches such as diet, herbs, supplements or other interventions that are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses.

6.9-Resources and Infrastructure Related to Cancer Control, Survivorship and Outcomes Research

Examples of science that would fit:

- Informatics and informatics networks.
- Clinical trial groups related to cancer control, survivorship, and outcomes research.
- Epidemiological resources pertaining to cancer control, survivorship, and outcomes research.
- Statistical methodology or biostatistical methods.
- Surveillance infrastructures.
- Centres, consortia, and/or networks.
- Education and training of investigators at all levels (including clinicians).
- Psychosocial, economic, political and health services research frameworks and models.

Figure 1 Percentage of Total NCRI Partners' Spend in Supportive & Palliative Care Research by CSO

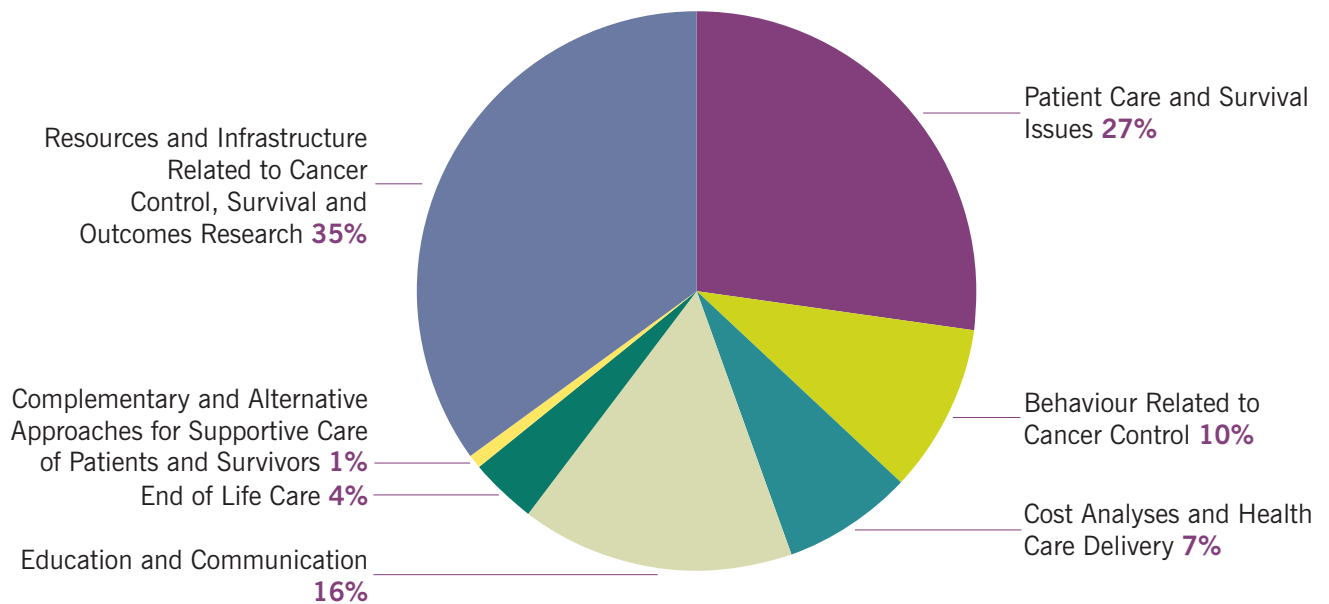


Figure 2 Organisation Spend in Supportive and Palliative Care Research by CSO Sub-Category

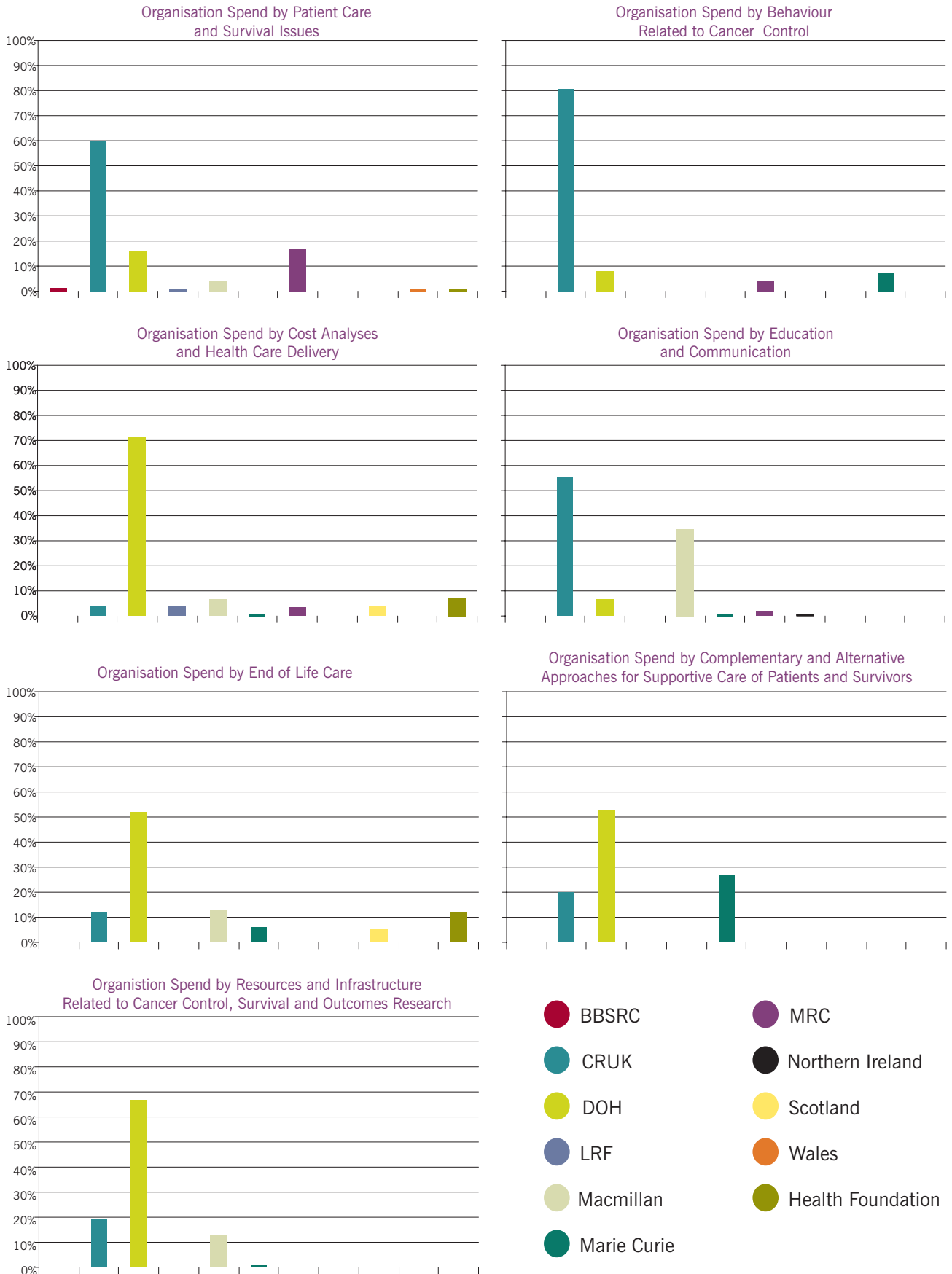


Figure 3 Percentage of Total NCRI Partners' Spend vs. Mortality by Tumour Type in Supportive & Palliative Care Research

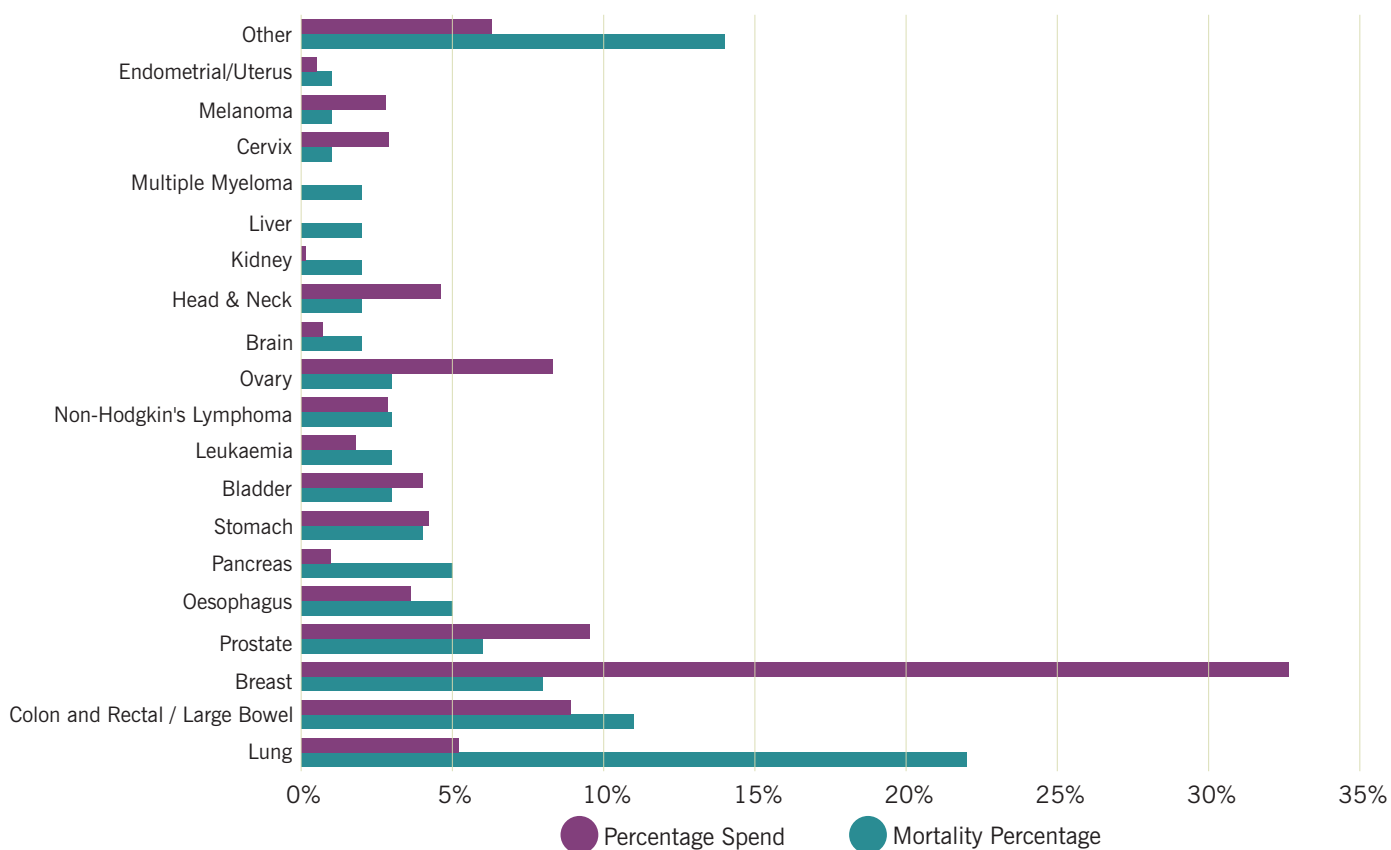
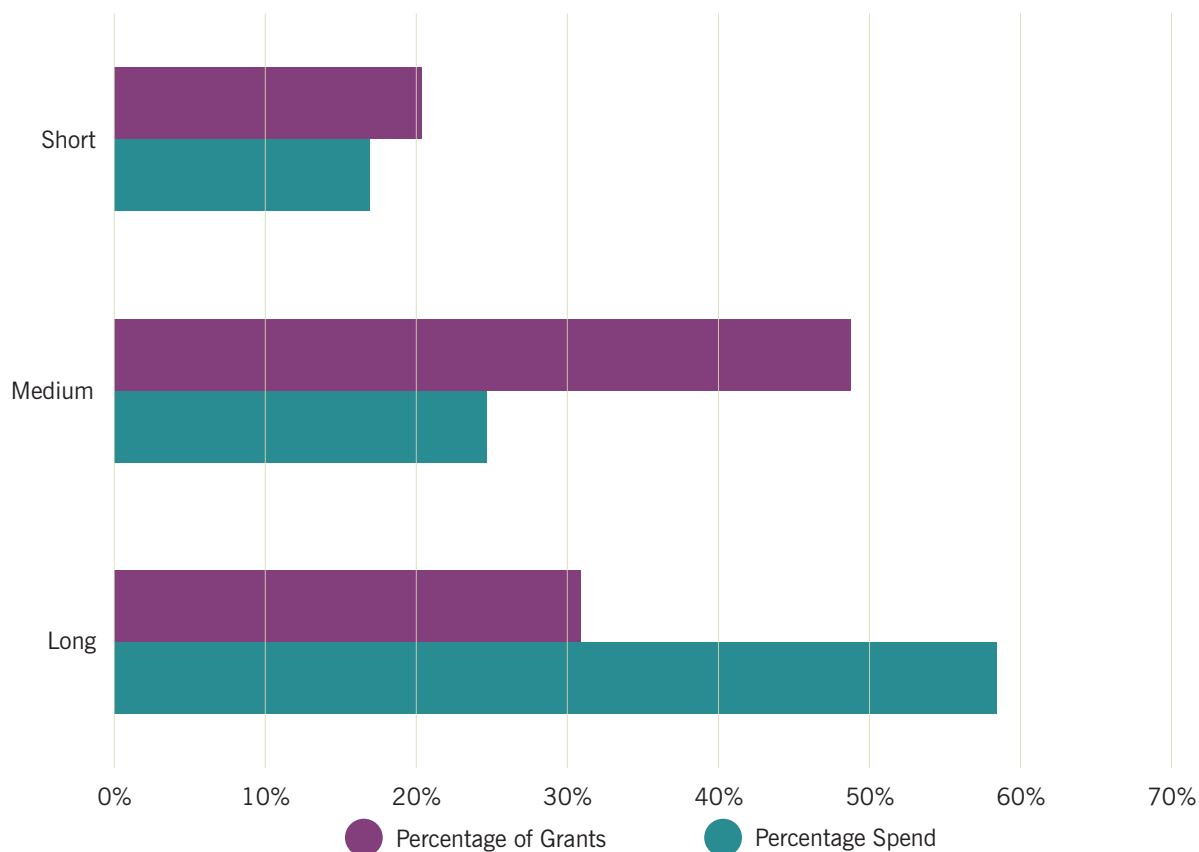


Figure 4 Duration of Funding in Supportive & Palliative Care Research (Excluding NCRN and NTRAC)



6 Strengths and Weaknesses in the Research Evidence Base

- 6.1 Professors Irene Higginson and Alison Richardson have completed a detailed review, including systematic reviews of the international literature, of the evidence relevant to the [NICE Service Guidance on Improving Supportive and Palliative Care for Adults with Cancer](#). This chapter reports their findings and considerations.
- 6.2 There is a lot of research evidence on needs, and on problems when care is not effective, but evidence on effective solutions is very patchy (good on communication, but scarce on spiritual care, co-ordination, and user involvement).
- 6.3 There is some research evidence comparing the importance of supportive and palliative care for patients with other health priorities. Research programmes have rarely answered questions in evolutionary steps, except research on communication skills training, which is to be commended. Research on specialist palliative care involves very different models and so is difficult to interpret in terms of what is best.
- 6.4 Interventions are often poorly defined and thus difficult to replicate. Services are often developed without evaluation, and there is a lack of comparative studies.
- 6.5 Study populations are often highly selected, with a lack of acknowledgement of the time course of the disease (there is a need to differentiate between early and advanced disease). There is a lack of studies on elderly groups and different cultural groups.
- 6.6 Outcome measures are extremely varied and are rarely collected in a systematic way. There is a need to develop measures for less tangible, patient-centred outcomes (e.g. hope). Many interventions are in fact 'complex', and would benefit from evaluation in line with the [MRC Framework for Evaluating Complex Interventions](#).
- 6.7 There is little justification for further studies on 'need' only. There is a need for:
 - o longitudinal studies of preference and experience;
 - o development and testing of different models and solutions;
 - o comparisons with 'current best practice';
 - o definitions of interventions, populations, and outcomes;
 - o outcome measures of complex interventions for use in clinical practice
- 6.8 Communications skills research is an area of success. This subject has benefited from larger research groups progressing with logical steps applying different approaches to the same questions with a common core approach. There has been a relatively large investment in this area for over 20 years. Groups have to compete every 5 years for programme grants but they can compete regularly for project grants. Another reason for success in this field is the fact that the focus is the professional rather than the patient.
- 6.9 Success has not been so great with information delivery, where the focus is the patient rather than the professional, and where methodology needs development (e.g. tools for measuring the extent of meeting patient information needs).
- 6.10 There are approximately 200 hospices and 400 home care teams all providing different services. There is a need to determine the best models of care through comparative and longitudinal research and evaluative studies.
- 6.11 There is a major need for rigorous intervention studies carried out by multi-disciplinary research teams.
- 6.12 Most research on symptoms has focused on pain. There is a need for research on symptoms such as breathlessness, fatigue, cachexia, agitation, depression, etc.

7 The Supportive and Palliative Care Research Workforce in the UK

OVERALL PICTURE

7.1 Questionnaires (see Appendix 2) were sent to 51 people identified as definite or probable research leaders in the field of supportive and palliative care. Responses were received from 45/51 (88%). Two respondents said that they were not actively involved in this field of research. The 6 people who did not respond were not thought to be running major research programmes.

Research Leaders

7.2 The disciplines of the 43 research leaders active in this field are shown in Table 2.

Staffing Levels

7.3 Overall staffing levels can be seen in Table 3.

7.4 Table 4 shows the distribution of the workforce (research and support staff) by size of the group and by the discipline of the lead researcher.

The 5 largest research groups (> 15 personnel) account for 37% of all staff

The next 4 research groups (10-14 personnel) account for 16% of all staff

The next 12 research groups (5-9 personnel) account for 29% of all staff

The last 22 research groups (<5 personnel) account for 18% of all staff

It can be seen that 5 of the 43 groups had 15 or more full-time equivalent staff - these

accounted for nearly one third of the overall staffing for the supportive and palliative care research workforce. Twenty-two of the 43 groups had less than 5 full-time equivalent staff, and 10 of these had less than 2 full-time equivalent staff. These 22 groups accounted for 18% of the overall staffing for the supportive and palliative care research workforce.

7.5 The 6 groups led by nurses were generally larger than others, with 4 of the 6 groups having 10 or more staff.

7.6 The one group led by a health service researcher was also relatively large, with over 20 staff.

7.7 The 15 groups led by psychiatrists/psychologists tended to be medium in size. Only 3 had more than ten staff, with a further 5 having between 5 and 9 staff.

7.8 The groups led by consultants in palliative medicine tended to be small with 8 of the 11 groups having less than 5 staff (of which 4 had less than 2 research active members).

Professions of the Research Workforce

7.9 The professions of the researchers were reported for 295 of the 330 research staff (89%). Nurses constituted the largest single group (99/295 = 34%), followed by psychologists (78/295 = 26%).

Table 2 Research Leader Disciplines

Disciplines of Group Research Leaders	No. of groups
Psychology/Psychiatry	14
Palliative Medicine	11
Nursing	6
General Practice	4
Social Sciences	3
Oncology	2
Health Services Research	1
Pain	1
Primary Care Education	1
Total	43

Table 3 Staffing Levels

	Total head Count	Full Time Equivalents
Research staff	330	241.2
Support staff	327	48.2
Total	657	289.4

Table 4 Workforce Distribution

		Total		Discipline of Research Leader								
		Groups	FTEs	Nursing	Health Services Research	Psychiatry / Psychology	Social Sciences	Palliative Medicine	General Practice	Oncology	Primary Care Education	Pain
Group Size	>20	3	74.0	2	1	0	0	0	0	0	0	0
	15 - 19	2	34.2	0	0	2	0	0	0	0	0	0
	10 - 14	4	46.2	2	0	1	0	1	0	0	0	0
	5 - 9	12	83.0	0	0	5	1	2	1	2	1	0
	2 - 4	12	42.0	1	0	4	0	4	2	0	0	1
	1	10	10.0	1	0	3	1	4	1	0	0	0
Total FTE		43	289.4	6	1	15	2	11	4	2	1	1

7.10 The total number of medically qualified staff was 62 (21%). This figure includes palliative medicine (32), GPs (9), psychiatrists (8), oncologists (3) and 10 for whom the medical discipline was not stated.

7.11 A range of professions was reported including sociology (18), epidemiology/public health (7), primary care education (7), anthropology (3), occupational therapy (3), and others (18).

Higher Degrees/Qualifications

7.12 118 (36%) of the research staff were reported to have doctorates, with a further 50 (15%) currently working towards a doctorate. A further 89 (27%) had other qualifications. The degrees/qualifications of the remaining 73 (22%) were not stated.

Age of the Research Workforce

7.13 The age of researchers was reported for 250 (76%) of the 330 staff. 31 (12%) of the staff with known ages were over 50 years, 29%

were 41 - 50 years, 38% were 31 - 40 years and 20% were 21 - 30 years.

7.14 The ages were reported for 32 (74%) of the research leaders. 13 (41%) were over 50 years; 12 (38%) were 41 - 50 years and 7 (22%) were 31 - 40 years.

Duration of Contracts

7.15 The duration of contracts was reported for 260 (79%) of the 330 research staff. 109 had permanent contracts; 31 had contracts for 3 - 5 years; 76 had contracts for 1 - 3 years and 44 had contracts for less than one year.

Areas of Research Interest

7.16 The most frequently reported area of research interest was psychological research (21 groups), following by information/communication (18 groups); physical symptoms/control (17 groups); service

delivery and organisation (16 groups); quality of life assessment (13 groups); end of life care (13 groups) and family and carers needs/support (11 groups).

7.17 In contrast, several areas of research were only reported as areas of major interest by relatively smaller numbers of research groups. These include complementary therapy research (5 groups); epidemiology/policy (5 groups); generic needs assessment (four groups); ethics research (four groups); rehabilitation (four groups) and social care research (three groups).

7.18 The equivalent picture restricted to the 22 groups with five or more staff (research and support) showed a broadly similar pattern shown in Table 5.

Location of research groups

7.19 23 (53%) of the 43 groups were located either in a teaching hospital or a cancer centre, with a further 15 (35%) being on a university campus but not attached to a hospital. Three units were based in primary care and two in hospices. Groups led by nurses and sociologists tended to be based on university campuses, whereas groups led by psychiatrists, psychologists, palliative medicine specialists and oncologists tended to be based on teaching

hospital/cancer centre sites.

Sources of funding

7.20 27 of the groups reported receiving funding from Cancer Research UK; 24 from the Department of Health; 15 from Macmillan Cancer Relief; 6 from the Medical Research Council; 8 from Marie Curie Cancer Care; 5 from the Sainsbury Family Charitable Trusts and 5 from the Health Foundation (formerly PPP). Levels of funding provided by these organisations are shown in Figure A4.

7.21 Individual research groups also received funding from multiple other sources. In general the sums involved were less than £100k. Important exceptions to this were grants in excess of £500k to individual research groups from other research councils and the European Union.

ANALYSIS BY DISCIPLINE

Psychology/Psychiatry

7.22 The survey showed that, of the 295 researchers who indicated their profession, 78 (26%) were psychologists, and seven (2%) were psychiatrists. Fifteen (35%)

Table 5 Number of Research Groups within Research Category

Research Type	No. of Research Groups*
Psychological research	12
Service delivery & organisation	12
Quality of life assessment	11
Information/Communication	10
Physical symptoms/control	10
Family and Carers	8
End of life care	7
Quality of care assessment	7
Methodology/outcome measures	7
Education research	5
Complementary therapies	4
Epidemiology/Policy	3
Generic needs assessment	3
Social care research	3
Laboratory research (e.g. pain)	3
Spiritual care research	2
Rehabilitation	1
Ethics research	1

*Groups containing 5 or more staff

research groups were led by psychologists or psychiatrists. These groups tended to be medium in size - only 3 had more than 10 staff, with a further 5 having between 5 and 9 staff. A further 10 groups had psychologists as members but were led by researchers from other professions.

- 7.23 Representatives from the NCRI Clinical Studies Development Group (CSDG) on Psychosocial Oncology, and the British Psychosocial Oncology Society, described the problems they faced. They felt that psychosocial research groups tended to work in 'silos' rather than collaboratively across groups, and with other disciplines. There was a lack of dedicated statistical support and methodological advice.
- 7.24 Researchers felt that there was a lack of career structure, especially a lack of senior lecturers, which was resulting in a missing cohort of research leaders for the future. Service posts were more secure, and thus more attractive, than time-limited research posts. Researchers in service posts found it hard to protect their time for research due to service pressures. Researchers also felt that research was not linked with education and training so that research was an isolated activity.
- 7.25 A number of methodological hurdles were holding back progress. For example, a lack of easy measures of subjective outcomes for use in trials, and the need to develop electronic forms of outcome measures (completed on computers in clinics by patients) for direct transfer of data from the clinic to the trials office.
- 7.26 Researchers flagged several research gaps including:
- o lack of incorporation of ethnic minority values;
 - o lack of proper harm/benefit analyses;
 - o lack of research on the molecular mechanisms of psychosomatic linkage;
 - o 'survivorship';
 - o late effects in adults;
 - o information delivery to patients;
 - o the link between social deprivation and poor outcomes; and
 - o the evaluation of psychosocial interventions including who should deliver them and what competencies are required.

- 7.27 The SPG felt that high quality psychosocial oncology was rated highly by the Research Assessment Exercise.

Palliative Medicine

- 7.28 The survey showed that, of the 295 researchers who indicated their profession, 32 (11%) were palliative medicine doctors. A further 10 (3%) researchers were medics who did not state their discipline. Eleven of the 43 (26%) research groups were led by consultants in palliative medicine. These groups tended to be small with 8 of the 11 groups having less than 5 staff (of which 4 had only one research active member). A further 3 research groups had palliative medicine doctors as members.
- 7.29 Palliative medicine representatives from the NCRI CSDG on Palliative Care described the problems they faced. Statistical support and methodological advice were hard to obtain, and there was a lack of collaboration between research groups, and between disciplines. However, a lot of enthusiasm had already been created by simply establishing the CSDG - there had been a lot of applications for membership.
- 7.30 There was a major issue with research career structures - service posts were long term and secure compared to time-limited research posts. Service pressures were such that, for those in service posts, time for research (and teaching) was limited. SPG members were concerned that the offer of new research fellowships would not yield high quality applications, and that it might not be possible to guarantee the quality of the training - the SPG noted that there was no international standard palliative medicine research in the last HEFCE Research Assessment Exercise.
- 7.31 Researchers reported that there were methodological barriers such as: practical measures of outcomes other than survival (customised for aspects such as fatigue and cachexia); definition of the patient population; when to refer, and who decides; and accrual attrition and missing data (the SPG suggested that a possible solution to the latter was to start research earlier in the

course of the disease).

- 7.32 Another problem raised was the difficulty in accessing patients especially in primary care. Clinicians are naturally 'protective' of their patients and are anxious about exposing them to perceived onerous research processes.

Nursing

- 7.33 99 (34%) of the 295 researchers who stated their profession were nurses. The 6 groups led by nurses were generally larger than others, with 4 of the 6 groups having 10 or more staff - 2 of these groups had more than 20 staff. A further 18 groups had nurses as members. Thus a total of 24 groups (56%) included nurses as members. Cancer nursing researchers confirmed that nurses in the larger units were indeed focused on cancer research rather than other disease areas. Numbers were swelled by NCRN research nurses. A lot of work was underway to train researchers, so the numbers were swelled by doctoral students. Indeed the survey revealed that 14 (16%) of the researchers whose profession was stated as nursing were doctoral students.
- 7.34 Two of the groups led by nurses had received Macmillan funding for some time, which had enabled research grouping.
- 7.35 Cancer nursing researchers reported that the general picture was one of a developing research capacity. Research was typically single-site small-scale studies linked to taught masters courses. There were only a small number of research groups (about 6) with research programmes. The publication profile of cancer nursing research has increased substantially over the last 20 years. There are now two dedicated journals, and the quality of accepted papers is improving.
- 7.36 Cancer nursing researchers described the problems they faced. There was a lack of infrastructure in the form of data management support and stable research assistance. There was also poor co-operation between existing groups. There was a need to avoid perpetuating professional silos. The nature of the research should determine the nature of the research leader, with questions being addressed by multidisciplinary teams.
- 7.37 There was a lack of career structure. The questionnaire survey revealed that many contracts were permanent, but nursing researchers clarified that these contracts were service contracts. Most research contracts were relatively short (i.e. lack of university tenure) and researchers had to resort to teaching and service posts to fill in gaps between research contracts. The problem was particularly acute at post-doctoral level. This had resulted in a lack of high quality researchers.
- 7.38 There was also a definite academic/clinical split in nursing, which was much more pronounced than in other disciplines. There was a deep ambivalence within nursing around accepting an academic elite. Research was isolating - it was perceived as 'alien' - researchers were not seen as clinical staff. Exposure of nurses to research pre-registration was minimal so they did not see the benefits of research.
- 7.39 Compared with other clinical academics it took much longer to be a researcher in nursing. Years of clinical experience were required before academic training started. Other countries have fast-track schemes - they do PhDs earlier. In addition service pressures meant that Senior Clinical Lecturers got sucked back into clinical practice - they had no entourage/juniors to support them. When nurses were removed from the clinical setting they lost their grounding and became a 'visitor'. This meant that clinical updates were required subsequently before patient contact was permitted.
- 7.40 SPG members noted that nursing researchers were not perceived seriously enough by other disciplines for them to truly collaborate. It was suggested that a more helpful description would be "researching elements of patient care" rather than "nursing research".
- 7.41 SPG members noted that Nurse Consultant contracts did not specify research, and that research was not needed to become a Nurse Consultant. Further, Nurse Consultants did not have clinical support teams. It was also

noted that a major cancer hospital received significant NHS R&D Support, but the Trust had not chosen to invest any significant amounts in funding research time for nurses.

- 7.42 Nursing researchers also identified lack of methodologies and outcomes measures as barriers to progress.
- 7.43 Research opportunities highlighted by nursing researchers included: development of non-drug interventions; continuity of care; inequalities of access; treatment decisions; support needed to enhance self-care; emotional care; morbidity profiling across the UK; intervention studies; innovative use of IT; changing professional/patient/carer behaviour; and establishing a data stores of patient experiences to map trajectories of problems over time.

General Practice

- 7.44 Nine (3%) of the 295 researchers who stated their profession were GPs. The 4 research groups that were led by GPs were small - only one had more than 5 staff. Only one further group had a GP as a member.
- 7.45 GP representatives from the NCRI CSDG on Primary Care noted that primary care was integral throughout the cancer journey for patients and families. Most patients preferred to die at home, but although most of the last year of life was spent at home, most patients were admitted to hospital to die. It was for these reasons that much of the NHS Cancer Plan involved primary care.
- 7.46 Primary care cancer researchers were enthusiastic but there was little history of research in this area and little structure. There was a lack of senior academics, as well as academic and clinical isolation. Research was fragmented and usually disease site specific with a paucity of trials and multi-centre research. There had been only limited engagement to date with the NCRN.
- 7.47 There had been considerable research capacity initiatives over the last 6 - 7 years in the form of new fellowships and ear-marked grants. Researchers felt that it would be important for this to continue. The NCRI CSDG in Primary Care was also seen as a very important

development enabling better integration of primary care with the other Clinical Studies Groups. The community was therefore small, but growing.

- 7.48 GP researchers reported that there was a challenge in actively engaging primary care in the research process - research was not in the GP contract. However, SPG members noted that primary care received £15m of NHS Support for Science R&D funds, and that most of this was for GP time. The NHS Primary Care R&D Networks cover the whole of England and this should provide a strong basis on which to work.
- 7.49 SPG members agreed that GP researchers were rightly modest about their capacity. However, there was clear potential for the four groups to form a network with a focussed programme.

- 7.50 There might also be potential for further collaboration capacity for multi-centre research through the MRC General Practice Research Framework (GPRF).

Social Science

- 7.51 21 (7%) of the 295 researchers who indicated their discipline specified social science (e.g. sociology, anthropology). The 2 research groups that were led by social scientists were small - one consisted of 7 researchers, and the other was a single researcher. Eight other groups had social scientists as members, one of these groups included 5, and one included 4 social scientists.
- 7.52 Social science researchers explained that one of the strengths of their discipline was the acceptability of many of their methods to practitioners and patients (e.g. story telling). In addition, access to patients was not perceived as difficult because this was a fundamental element of social science training - specific techniques and approaches had been developed. Social scientists were always working in foreign environments - so they anticipated problems, which possibly health professionals did not.

7.53 SPG members noted that social science was not in such a 'silo' as other specialties. Indeed, specialisation in cancer was considered to be confining, particularly in end of life care, and bereavement. Links with research on old age and medical sociology were strong.

7.54 Social science researchers gave their views on the barriers. The main perceived barrier was research careers. Attracting people to the field was not a problem. The real problem was retention, particularly after PhD and early post-doctoral phase i.e. creating independent researchers. Social scientists were not able to bridge gaps between research grants by working in the NHS as locums. There was a lack of career opportunities in universities.

7.55 There was also a perceived lack of response-mode funding opportunities, particularly since the demise of the NHS R&D regional response-mode schemes. These schemes had enabled researchers to generate and explore their own ideas progressing logically from one step to the next along the research process. Research projects could thereby be seen through to the end, and then developed further. Useful cohorts of researchers had been created. A certain researcher had been successful in winning a number of these grants and felt that this had been instrumental in gaining university tenure. An important feature of these grants, in the particular case cited, had been that they included 40% overheads thus fulfilling the overhead target set by many medical schools.

7.56 It was noted that the Economic and Social Research Council (ESRC) was an important research funder in this discipline, and that there may be opportunities for joint working in any NCRI initiative that was developed (e.g. Co-operative Award in Science and Engineering (CASE) studentships).

7.57 Social science researchers described several important research opportunities. For example:

- o Do patients really want to die at home? Patients change their minds as their disease progresses. What is dying at home really like? It may not be based on the best care.
- o Children's bereavement services How are they managed, and what is good quality care? Are we causing any harm?
- o Other assumptions requiring challenge

included:

'Cancer is a chronic disease'; 'User involvement is good'; and 'Talking about disease is good'

- o What does cancer mean to people in the 21st century?

The previous social construct was one of 'hopelessness' and 'stigma', a new paradigm is now required.

- o Euthanasia as part of advanced care planning

(evidence from hospices shows that loss of control and dependency govern requests more than pain)

- o Sociology of organisation and management

How to organise care

- o 'Networks'

How do they work in other areas

e.g. business networks

- o Changing the behaviour of health professionals

e.g. palliative care in the community - simply educating GPs may not be enough

- o Multi-disciplinary teams

these have not been studied adequately

Health Services Research

7.58 Seven (2%) of the 295 researchers who indicated their discipline were health services researchers (e.g. public health, policy, epidemiology). The one group that was lead by a health services researcher was large, containing 20 researchers. Only one other group had a health services researcher as a member.

7.59 The health services researcher who led their own group described major barriers to future research. The first of these was the 'drying up' of research funding sources, which had implications for staff retention. There was also considerable concern about the poor perception of palliative care research within universities. This was felt to be reflected in a generally poor outcome for palliative care research in the Research Assessment Exercise (RAE). The loss of NHS R&D regional responsive schemes had been a particular blow (see 'Social science' above). The availability of grants from non-cancer medical research charities had also decreased due to the effects of the stock

market - palliative care research was not perceived as central to their mission (e.g. British Heart Foundation, Stroke Association).

- 7.60 Lack of availability of grants had major impacts on staff retention - staff looked for their next job some months before their current grant expired. There was therefore the risk of not only losing valued staff but also of problems completing current research if they left before the end of the study. The group leader's time is therefore spent trying to obtain funds to keep staff going at the expense of writing up and disseminating completed research. A confounding factor was European legislation that would make it impossible to offer more than two short-term contracts in a row.
- 7.61 Research infrastructure in the form of statisticians, data analysts, secretarial and administrative support was also lacking - palliative care suffered within universities from being a new discipline trying to grow in a climate of financial cuts and funding constraints, particularly in medical schools. Academia was an increasingly unforgiving environment. The financial penalties for an institution doing badly in the (RAE) were huge and made it increasingly unlikely that universities would support, or even tolerate, research which was not perceived as being of at least national importance.
- 7.62 Research opportunities highlighted by researchers included research into the causes and treatment of breathlessness (see Chapter 6).

8 Proposed Way Forward

Organisational Issues

- 8.1 The major problem with the supportive and palliative care research workforce is its fragmentation across multiple sites, with relatively little interdisciplinary and/or interprofessional working, and relatively little collaboration with researchers outside the field of cancer. The overall number of researchers may not be inadequate - the challenge is to achieve genuine collaborative working.
- 8.2 The fragmentation of research in this field is already being addressed in part through the establishment of NCRI CSDG on: Palliative Care; Psychosocial Oncology; Primary Care; and Complementary Therapies. However, the main focus of the CSDGs is the development of multicentre randomised large scale (Phase III) trials. Many of the questions in supportive and palliative care require research methodologies other than trials. In addition, the trial interventions in this area are often "complex" in nature and therefore require greater development work that can encompass several research disciplines. Therefore, in addition to the CSDGs, *the SPG recommends that consideration be given to the establishment of interdisciplinary NCRI Supportive & Palliative Care Research Collaboratives, building on the experience of the NCRI Prostate Cancer Research Collaboratives.* The model for the Research Collaboratives should include pump-priming funding for pilot studies to support collaboration between the Research Collaboratives and external groups. A separate, more detailed, proposal on this has been prepared.

Workforce Issues

- 8.3 PhD training provision is good. However, there are inadequate numbers of postdoctoral fellows and senior lecturers to provide the future research leaders in the field. This is largely due to a lack of funded posts at these levels.
- 8.4 *The SPG recommends that NCRI Partners should be encouraged to establish postdoctoral and senior lecturer posts, linked to NCRI Research Collaboratives where possible.* The MRC has a Special Training Fellowship in Health Services Research scheme, for which candidates in the SUPAC area should be

encouraged to apply. The MRC has also recently launched a joint interdisciplinary research studentship and post-doctoral fellowship scheme with ESRC. In the future MRC hopes to work with ESRC to make Supportive and Palliative Care a priority area. Cancer Research UK will actively encourage applications to its existing fellowship schemes. The Department of Health is looking to highlight Supportive and Palliative Care as a priority area in its new generic personal award scheme to be launched by the National Coordinating Centre for Research Capacity Development in autumn 2004. In addition, Macmillan is looking towards funding a number of Research Fellowships in Supportive and Palliative Care.

- 8.5 Researchers with combined clinical and academic posts face serious difficulties in relation to pressures from service commitments. In contrast some researchers (especially nurses) work in units that are isolated from the clinical world, which also causes difficulties. In this respect *the SPG welcomes the new UK Clinical Research Collaboration (UKCRC) and its plans to address the general issues surrounding clinical academic careers.*
- 8.6 The Cancer Research UK panel that oversees the Supportive and Palliative Care Fellowships and Studentships and advises the Cancer Research UK Training Board on training in this area, reports that there is a very definite need for MSc-level research training. The panel observes that the UK is well behind several European countries and North America where such training has already been developed. *The SPG recommends that NCRI Partners should be encouraged to support the development of MSc training programmes in supportive and palliative care.*

Infrastructure Support

- 8.7 Few research groups have access to dedicated statisticians and methodologists who have appropriate expertise in this field. Resources for data management and administrative support are also scarce. *The SPG recommends that NCRI Partners*

should be encouraged to fund posts for statisticians, methodologists, and data managers, linked to NCRI Research Collaboratives where possible.

Funding

- 8.8 There is a perception that health services research in general was not adequately recognised, and hence funded, by the Research Assessment Exercise. This was particularly felt to be a problem for research in palliative medicine. However it was felt that high quality research in psychosocial oncology was assessed as high quality by the RAE.
- 8.9 The SPG recognised that a number of helpful steps had been taken that should strengthen the ability of the 2008 RAE to assess and reward health services research, public health research, and clinical research. These include the move to starred-quality profiles and the requirement that RAE panels ensure that excellence in practice-based and applied research is properly recognised. However the SPG also agreed that a considerable amount of work remains to ensure that this is successfully translated into action. Therefore *the SPG recommends that the NCRI Board should be asked to make representations to HEFCE (and equivalent bodies for other parts of the UK) regarding the value placed on health services research in general and on supportive and palliative care research in particular.*
- 8.10 Targeted funding may be needed to stimulate research into themes that are inadequately researched at present.

Methodological Issues

- 8.11 The difficulties in conducting research involving seriously ill patients with limited life expectancy needs to be recognised. Attrition of patients in clinical trials, and missing data, are particular issues within palliative care. The SPG noted that some research groups had already started to tackle this problem by commencing research earlier in the cancer patient journey.
- 8.12 There is a multitude of different outcome measures, with a major lack of consensus on which outcome measure is most appropriate for particular situations. This lack of consensus is

holding the field back. It makes systematic reviews, and peer review of research proposals very difficult. There is also a lack of practical but sophisticated measures of outcomes other than survival that are now recognised to be important to patients (e.g. 'hope'). There is a need for outcome measures that can be applied over the course of the patient journey to enable understanding of shifts over time. There may be a lot to learn from non-cancer areas e.g. sociology and social care. *The SPG recommends that workshops should be convened to address methodological issues, and in particular to define appropriate outcome measures for different aspects of research in this field.*

- 8.13 An additional methodological issue involves the difficulties around the evaluation of interventions in this area, which are often "complex" in nature. The SPG recommends the use of the MRC Framework for Complex Interventions. The SPG notes that the MRC has re-launched its grant schemes such that there are now mechanisms to support the earlier steps in the MRC Framework for Complex Interventions. *The SPG would encourage high quality applications from Supportive and Palliative Care research groups.*
- 8.14 Historically, the involvement of service users in research has not been strong. Involvement of users in research helps to maximise the impact of research on policy and practice. *The SPG recommends that service users be involved in all aspects of research.*

Membership of the Strategic Planning Group

Prof Mike Richards (Chair)

Cancer Research UK - (Jean King)

Department of Health - (Dr Russell Hamilton)

Medical Research Council - (Dr Angela Cooper or Dr George Sarna)

Macmillan Cancer Relief - (Tony Berry)

Marie Curie Cancer Care - (Dr Susie Wilkinson)

Patient representative - (Derek Stewart)

NCRI Secretariat - (Dr Liam O'Toole, Dr Helen Campbell)

Oral evidence sessions

The following groups accepted an invitation to present oral evidence:

- NCRI Clinical Studies Development Group on Palliative Care (Prof Geoff Hanks, Dr Chris Todd, and Dr Andrew Wilcock);
- NCRI Clinical Studies Development Group on Primary Care (Prof David Weller, and Dr Stephen Barclay)
- NCRI Clinical Studies Development Group on Psychosocial Oncology (Prof Mike Baum, Prof Lesley Fallowfield, and Prof Amanda Ramirez)
- British Psychosocial Oncology Society (Dr Peter Harvey and Prof Karen Cox)
- 'CAM in Cancer' Group of Charities (Dr Michelle Kohn; Dr Susie Wilkinson, Chris Head)
- Research evidence reviewers for the NICE Service Guidance on Supportive and Palliative Care (Prof Irene Higginson and Prof Alison Richardson)
- Cancer nursing researchers (Prof Jessica Corner, Prof Nora Kearney, Sarah Lister, Dr Alex Molassiotis)
- Social science and health service researchers (Prof Sheila Payne, Prof Julia Addington-Hall and Prof David Clark)

Objectives

The SPG was keen to obtain data on the current research workforce in the field of supportive and palliative care. It was recognised that researchers in this field come from diverse backgrounds e.g. psychiatry, psychology, palliative medicine, nursing, social sciences etc. The SPG was keen to get as clear a picture as possible of the number and nature of researchers in the field, and their research environment, across the UK.

Method

A questionnaire (Figure A1) was developed following piloting with a small number of research leaders. The questionnaire was sent out to research leaders identified from the National Cancer Research Institute (NCRI) Cancer Research Database, and the bibliography from the research outputs analysis. The distribution list for the questionnaire was enclosed with the questionnaire, and recipients were requested to suggest additional research leaders who should also be contacted.

Thirty-seven questionnaires were sent out by post and e-mail with a completion date of 30 May 2003, together with a copy of the initial distribution list. At their meeting on 6 June 2003, SPG members suggested additional groups and organisations to approach, which increased distribution to 51 research groups. At least one reminder was sent by e-mail to non-responders. A total of 33 had been returned by the extended deadline of 31 August 2003. This was a completion rate of 65%. At the meeting held on 29 September 2003, the level of response was considered to be insufficient for meaningful analysis. The Chairman, on behalf of the NCRI funders, therefore issued a formal letter by post and e-mail to

18 non-responders, which reiterated the purpose of the questionnaire. Specifically, it was considered important to obtain responses from primary care and social science units as the data received so far had been under-representative. Those with good reasons for not responding were asked to state them. A further 10 completed questionnaires and two other responses were received by the extended completion date of 31 October 2003.

Results

Recipients had been asked to pass the questionnaire to colleagues undertaking relevant research in other groups which were not already on the initial distribution list. Some evidence of this request was apparent. There was evidence also that researchers had discussed returns with colleagues within their group.

A total of 51 questionnaires were distributed and 45 responses (88%) were received. Two units declined to complete the questionnaire, one stating that their research areas were not relevant to the exercise and the other that their commitments were to service not research. The remaining 6 non-responders were not thought to be running major research programmes.

The analysis represents the data detailed on the 43 questionnaires received between the period May and October 2003. On some questionnaires data was missing or incomplete. The analyses includes those staff who were stated to be research-active. It does not include research students that were stated as being in the process of gaining a Master's degree, but it does include researchers studying for a doctoral degree.

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3. RESEARCH ENVIRONMENT

a) Physical Location

Please indicate the physical location of your Unit/Centre

Teaching Hospital	
Cancer Centre / not Teaching Hospital	
District General Hospital / Cancer Unit	
Primary care	
Hospice	
University campus not attached to a hospital	
Other (please describe)	

b) Managerial Links

Is your Unit / Centre managed within a:

University Department of Oncology / Cancer Medicin	
University Department of Psychiatry	
University Department of Anaesthetics / Pain control	
University Department of Behavioural / Social Sciences	
University Department of Nursing	
Other University Department (please state)	

If your Unit / Centre is not managed within a University please describe what academic support you have:

c) Academic Links

Please describe any key links, within or outside your Unit / Centre, for research purposes (for example a Department of Palliative Medicine might have close links with a Department of Psychiatry but be managerially linked to Oncology):

4. APPOINTMENTS

Do any staff in your Unit / Centre have any relevant research appointments (e.g. Grant awarding bodies; Research Advisory Groups; Research Network Leads etc.)? Please give details OR attach brief Cvs such as those used for research grants applications

5. FUNDING

In the last five years what have been your main sources of research funding (and amounts)

	<£50K	£50K - £100k	£101K - £200K	£201K - £500K	>£500K
Cancer Research UK					
Medical Research Council					
Department of Health					
Macmillan Cancer Relief					
Marie Curie Cancer Care					
The Sainsbury Family Charitable Trusts					
The Health Foundation (formerly PPP)					
Other (please state)					

6. RESEARCH TOPICS

We are interested to get a clearer picture of the breadth of current research activity. Please use the table below to indicate the research topics that your Unit / Centre is currently researching. (Feel free to send an annual report, or equivalent, as well if you wish)

Research topic	Major area?	Also Active?
Information / Communication		
Physical symptoms / control		
Psychological research		
Social care research		
Spiritual care research		
Generic needs assessment		
Quaality of life assessment		
Quality of care assessment		
Rehabilitation		
Complementary therapies		
Family & carers needs / support (including bereavement)		
End of life care		
Supportive / Palliative care service delivery & organisation		
Laboratory Research (e.g. into pain)		
Ethics research		
Education research		
Epidemiology / policy		
Methodology / outcome measures in palliative care		
Others (please specify)		

Figure A2 Physical Location

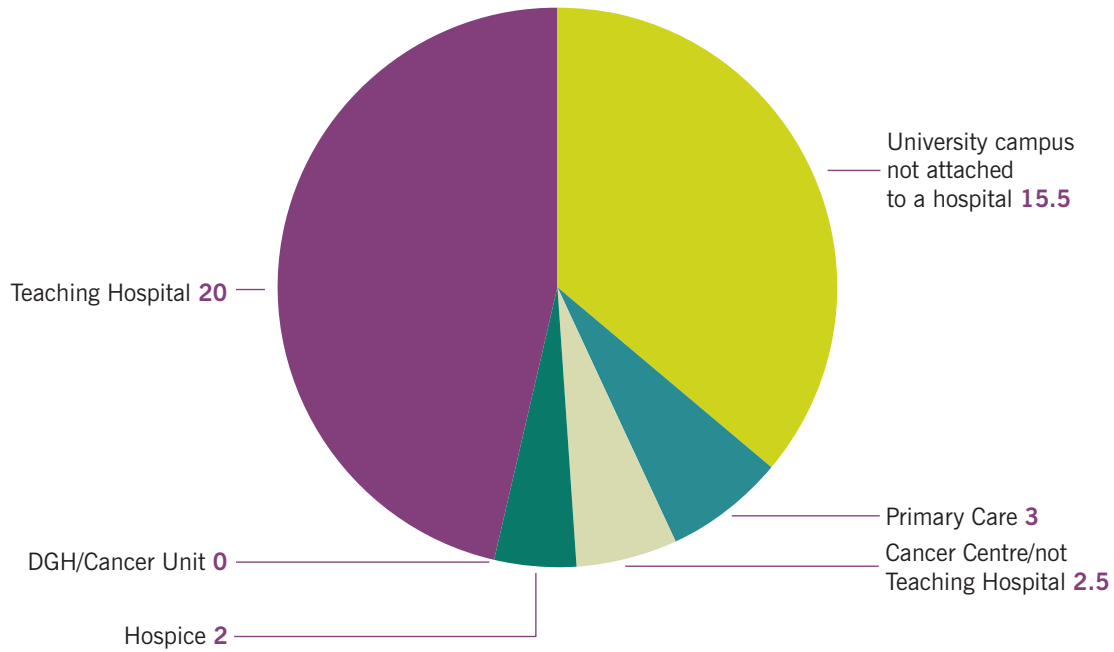


Figure A3 Managerial Links

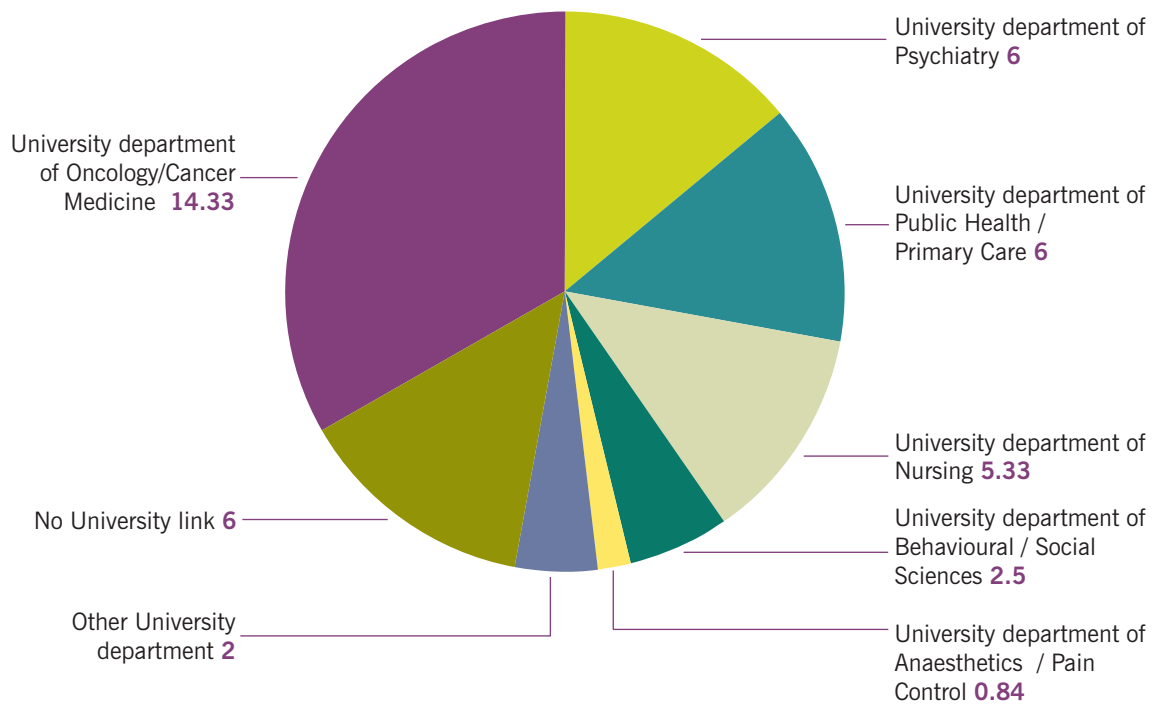


Figure A4 Unit / Centre Funding



Figure A5 Duration of Contracts

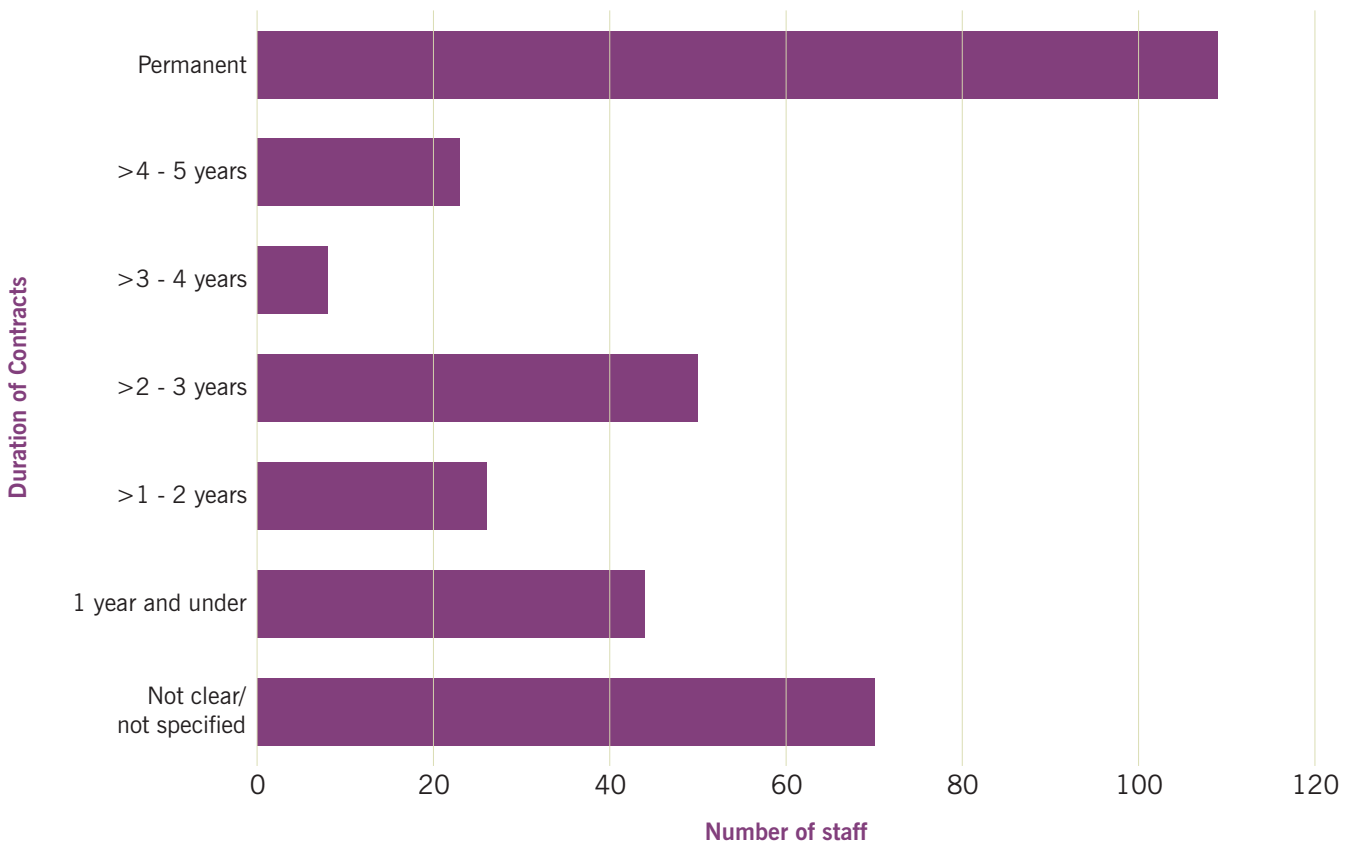


Figure A6 Profession / Discipline of Research Staff

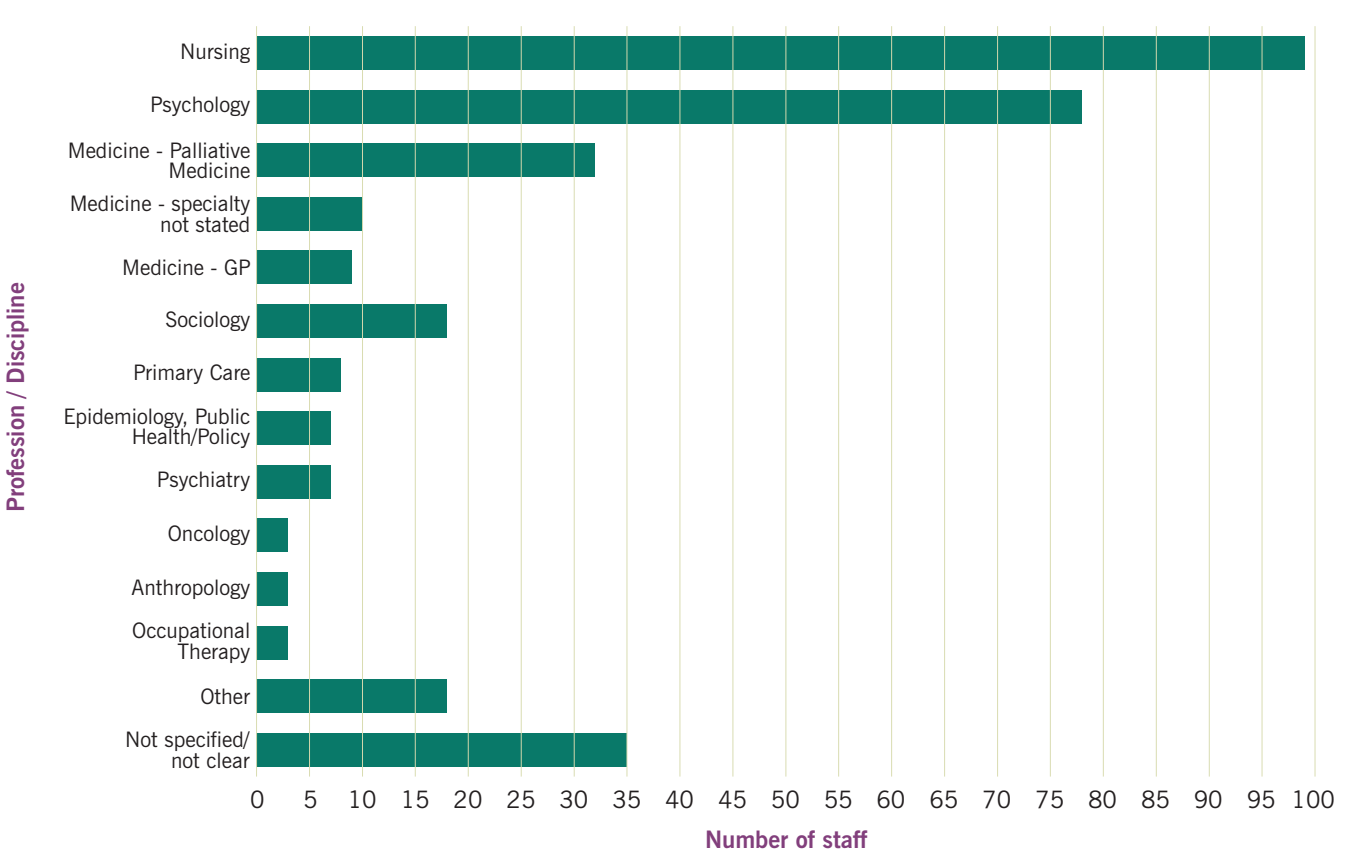


Figure A7 Contract Duration by Discipline

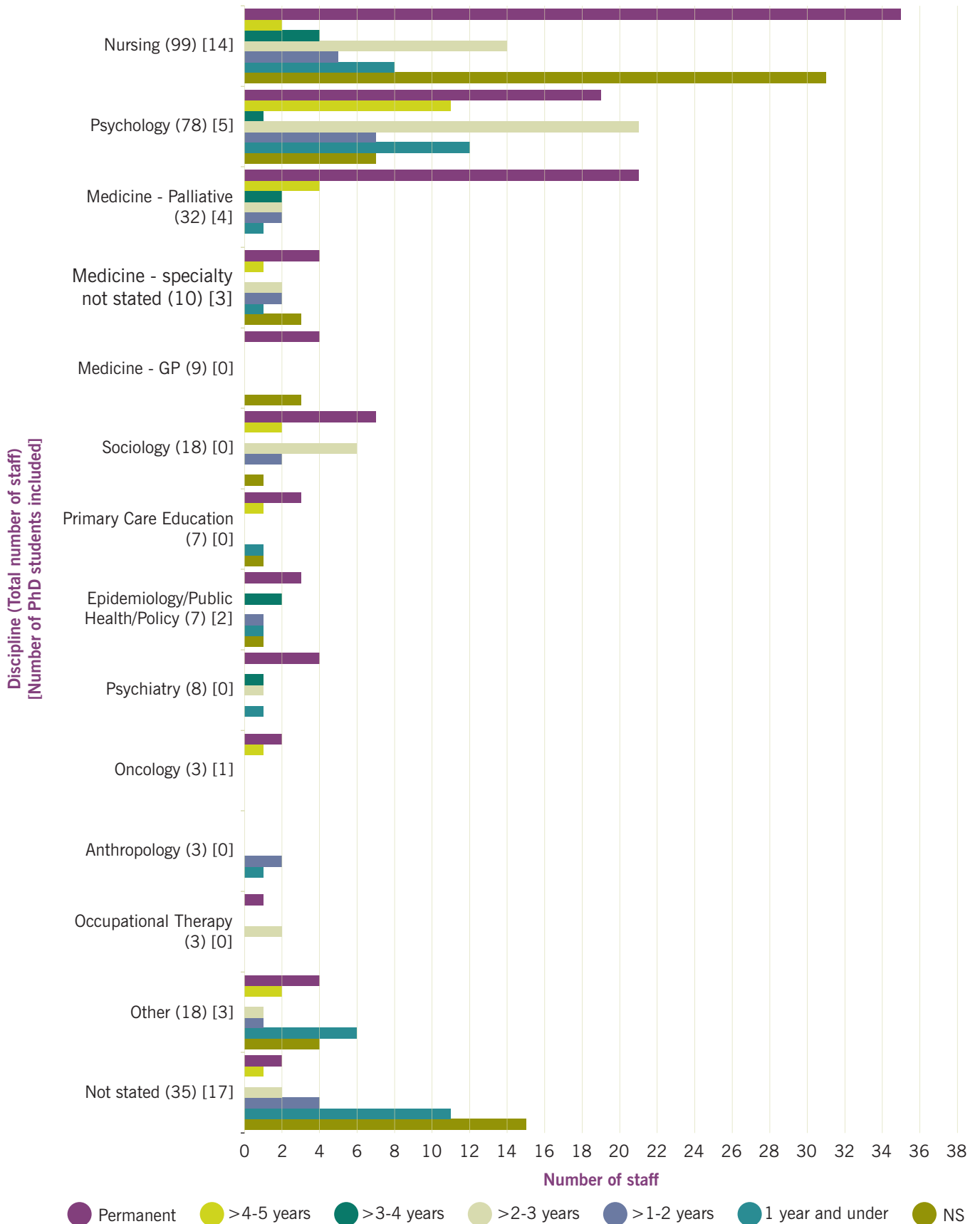


Figure A8 Higher Degrees

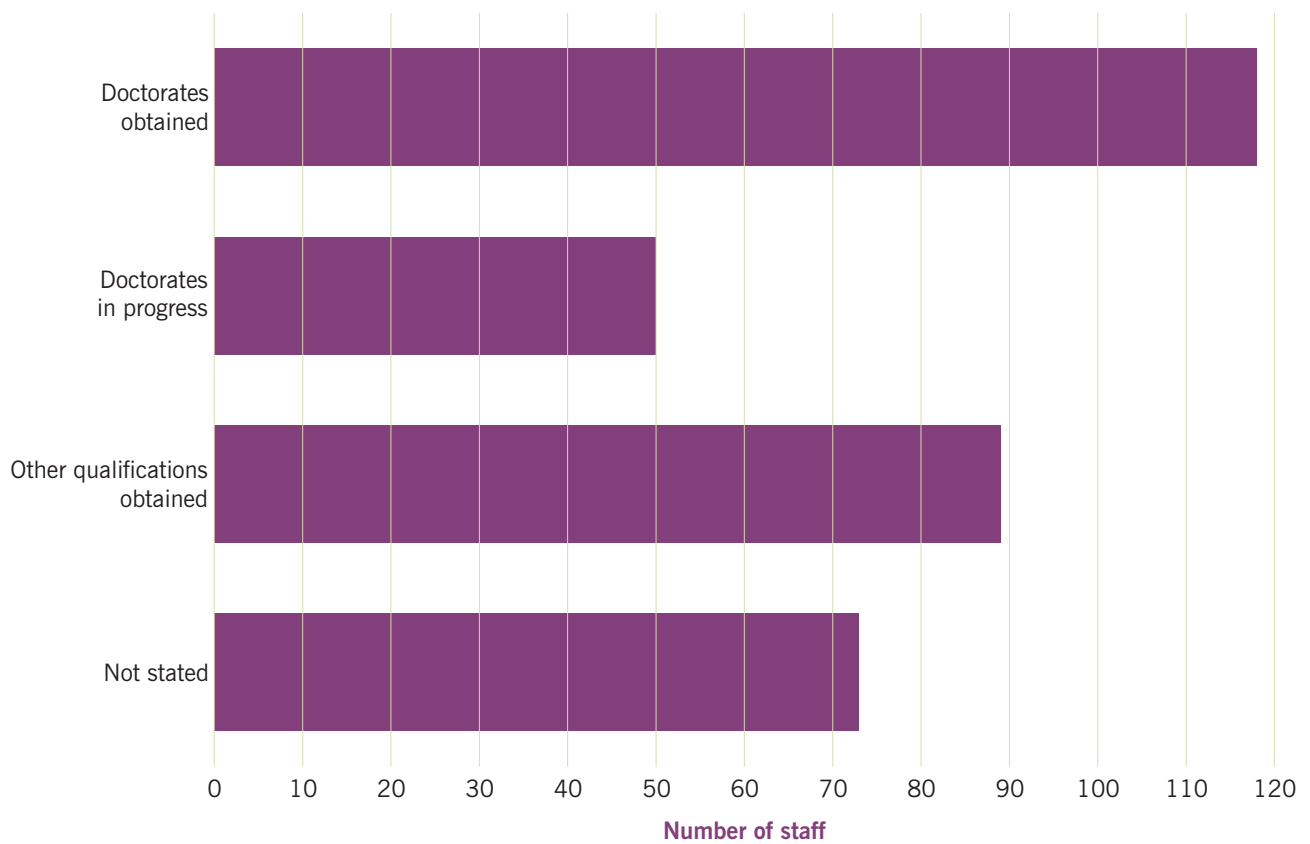


Figure A9 Research Staff by Unit / Centre

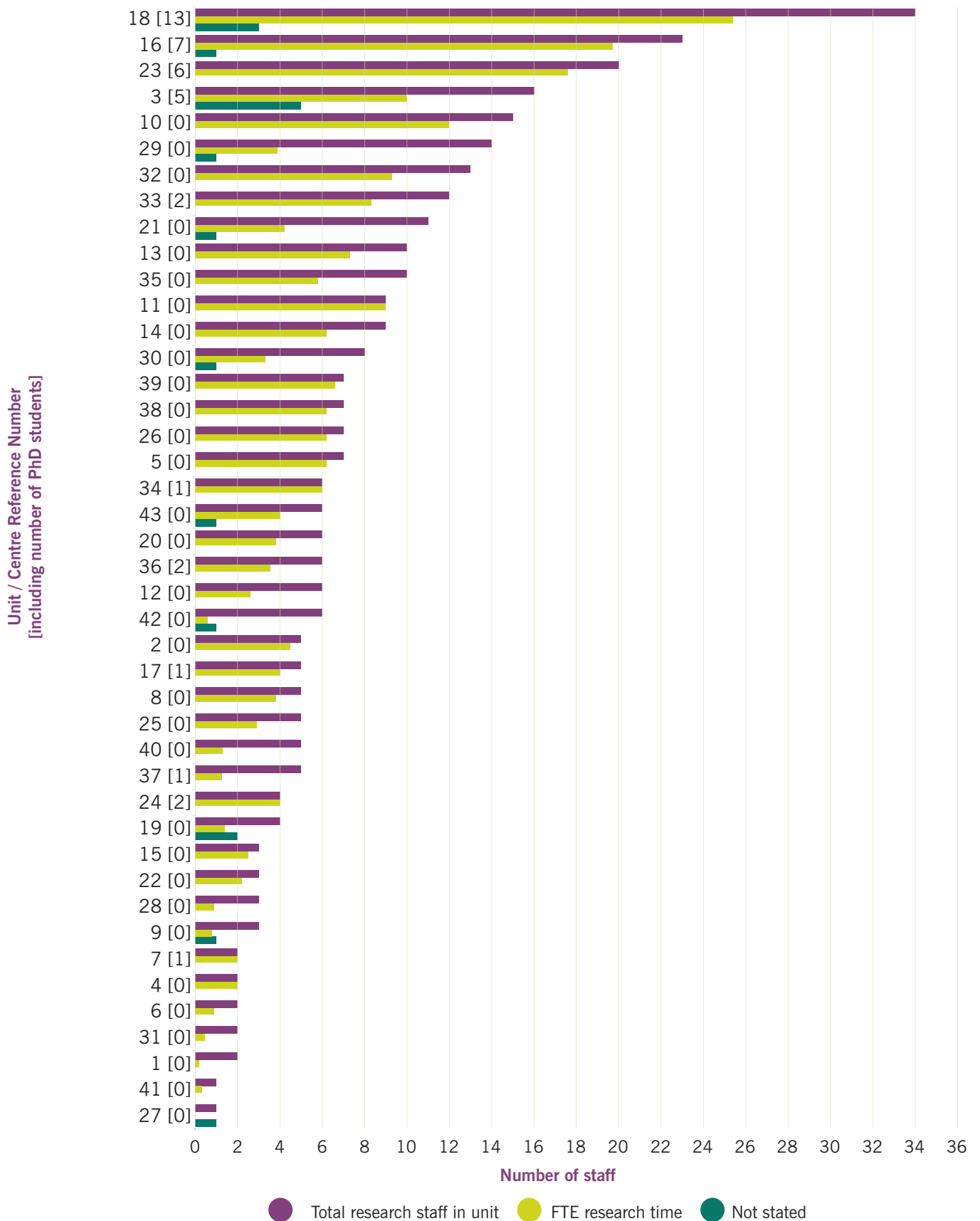


Figure A10 Research Groupings by Discipline of Lead Research

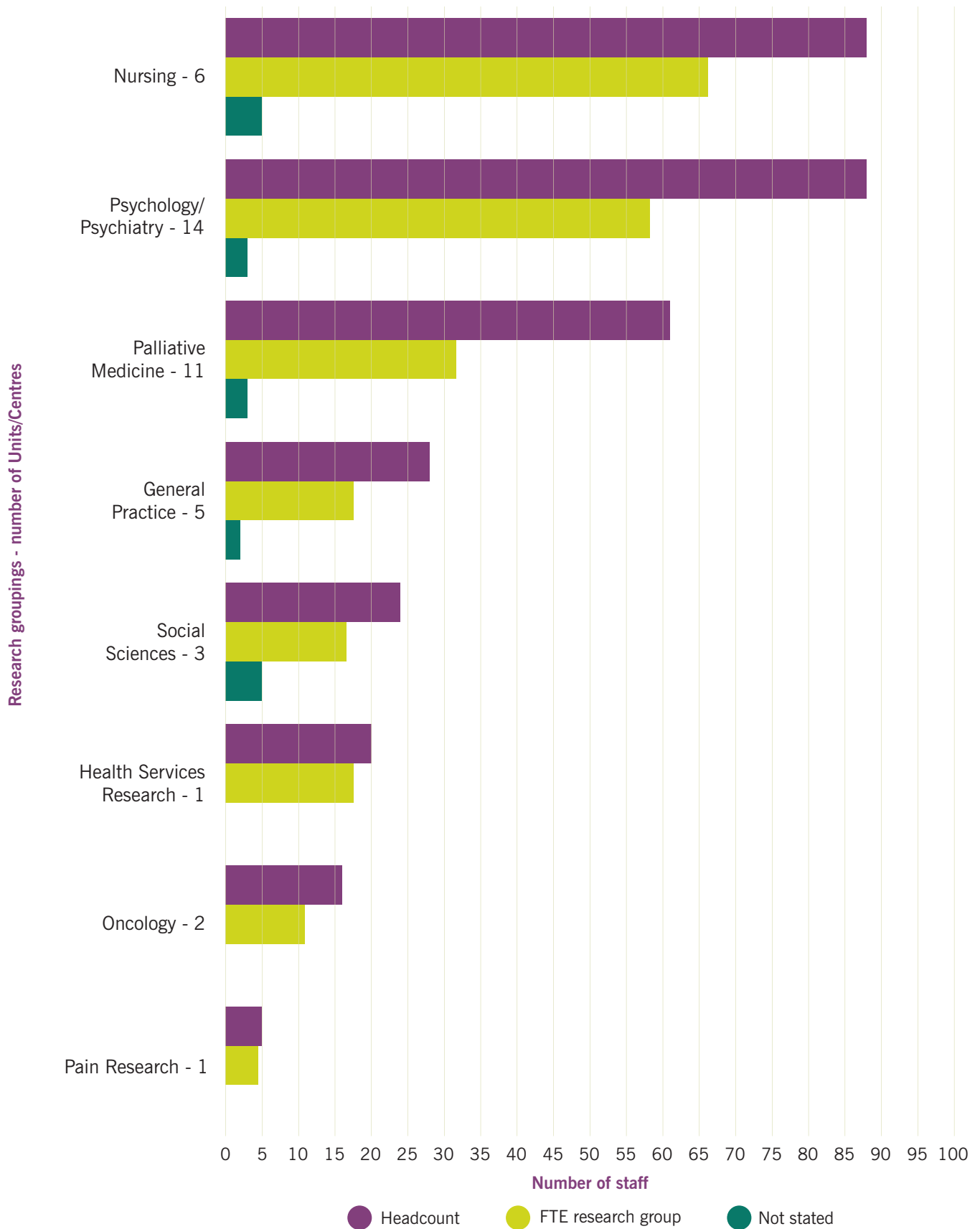


Figure A11 Size of Units / Centres

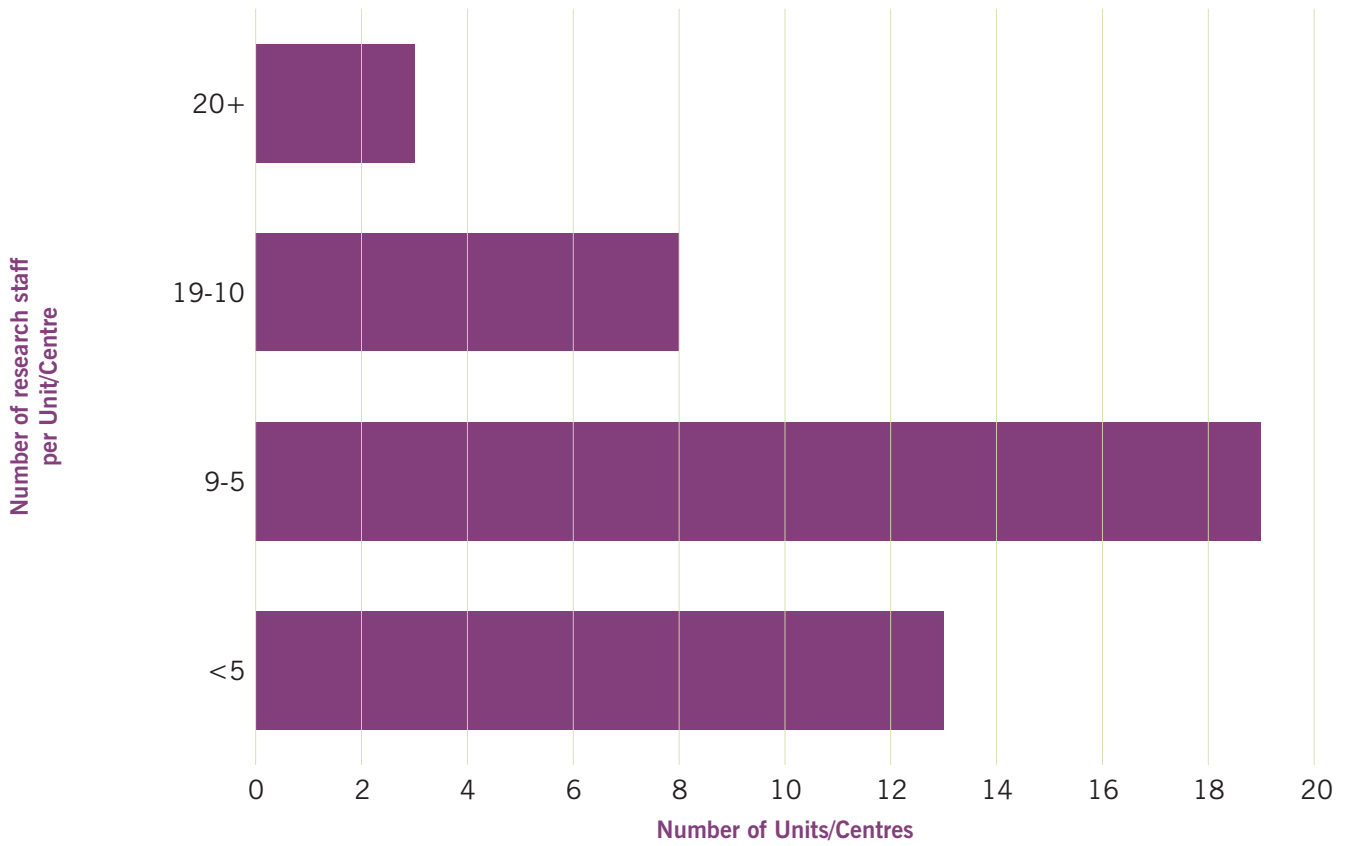


Figure A12 Age of Staff

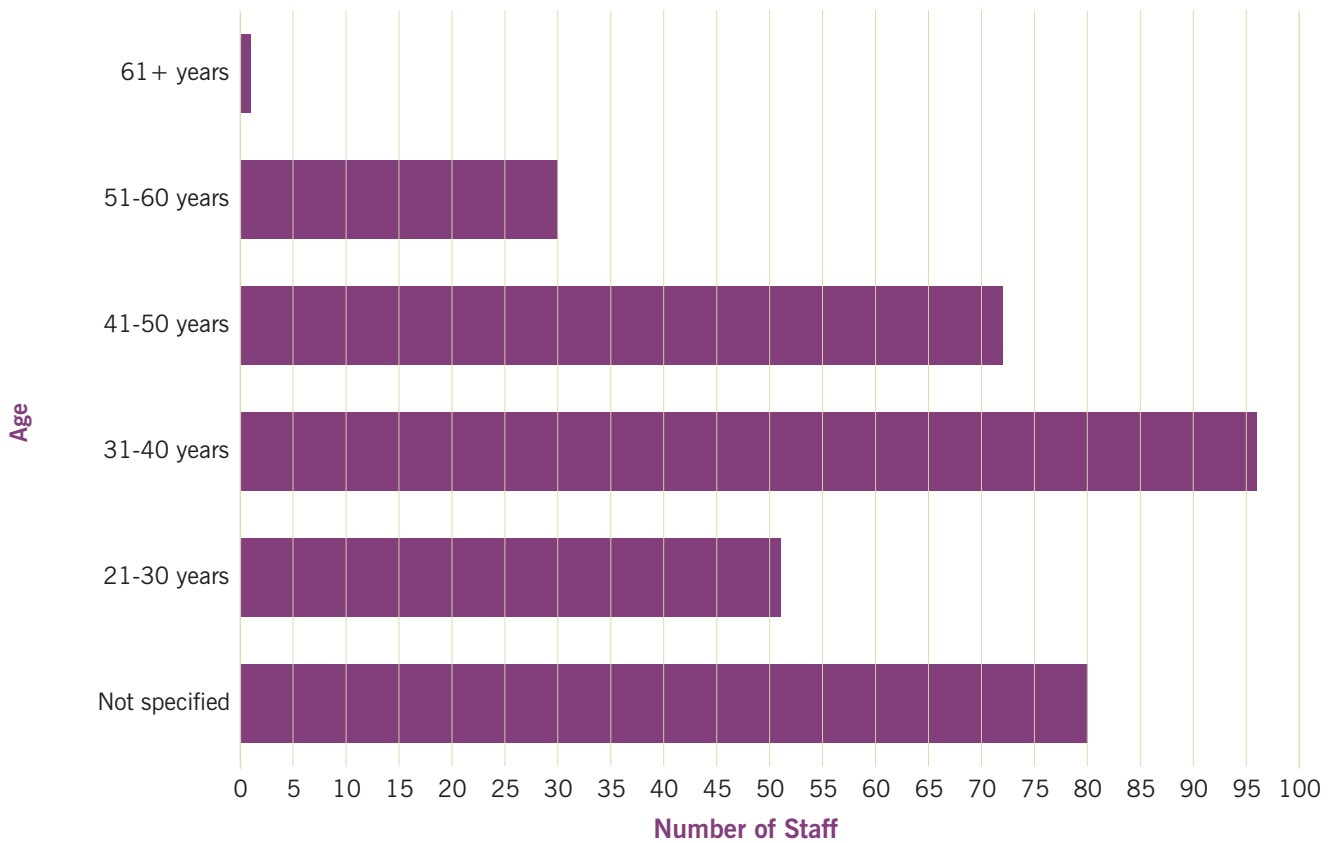


Figure A13 Ages of Unit / Centre Leaders

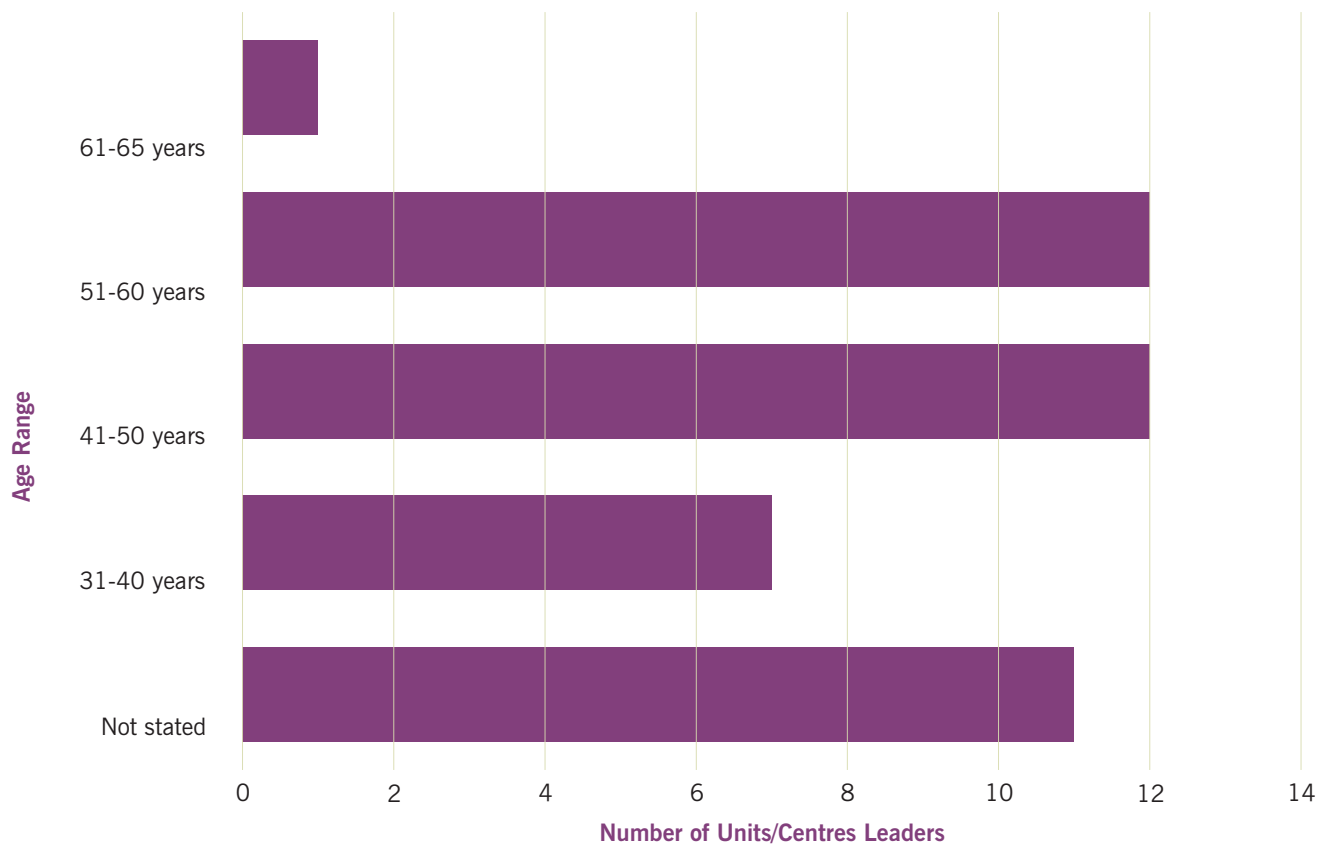


Figure A14 Age of Research Staff by Profession / Discipline

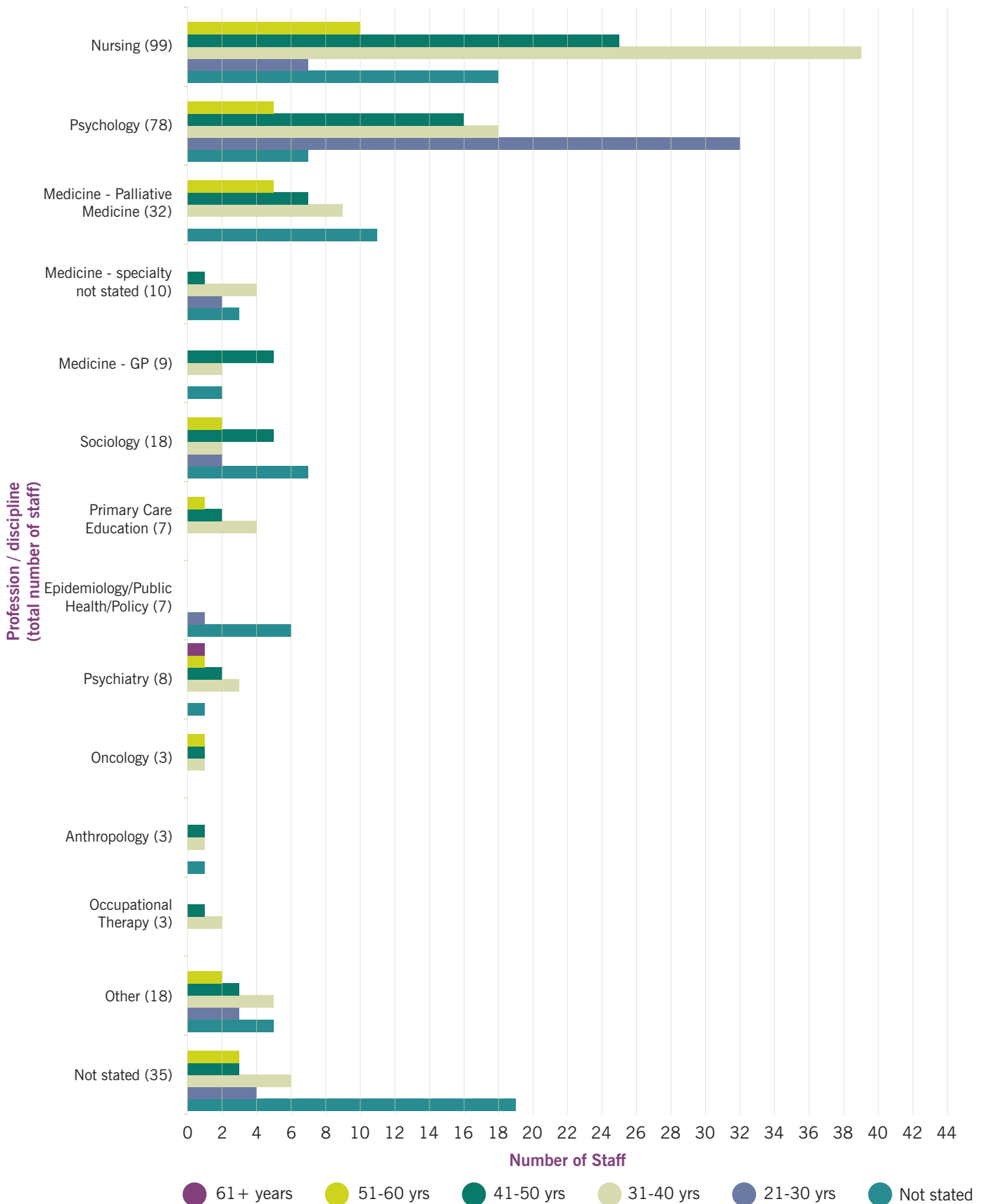


Figure A15 Research Support Staff (FTE)

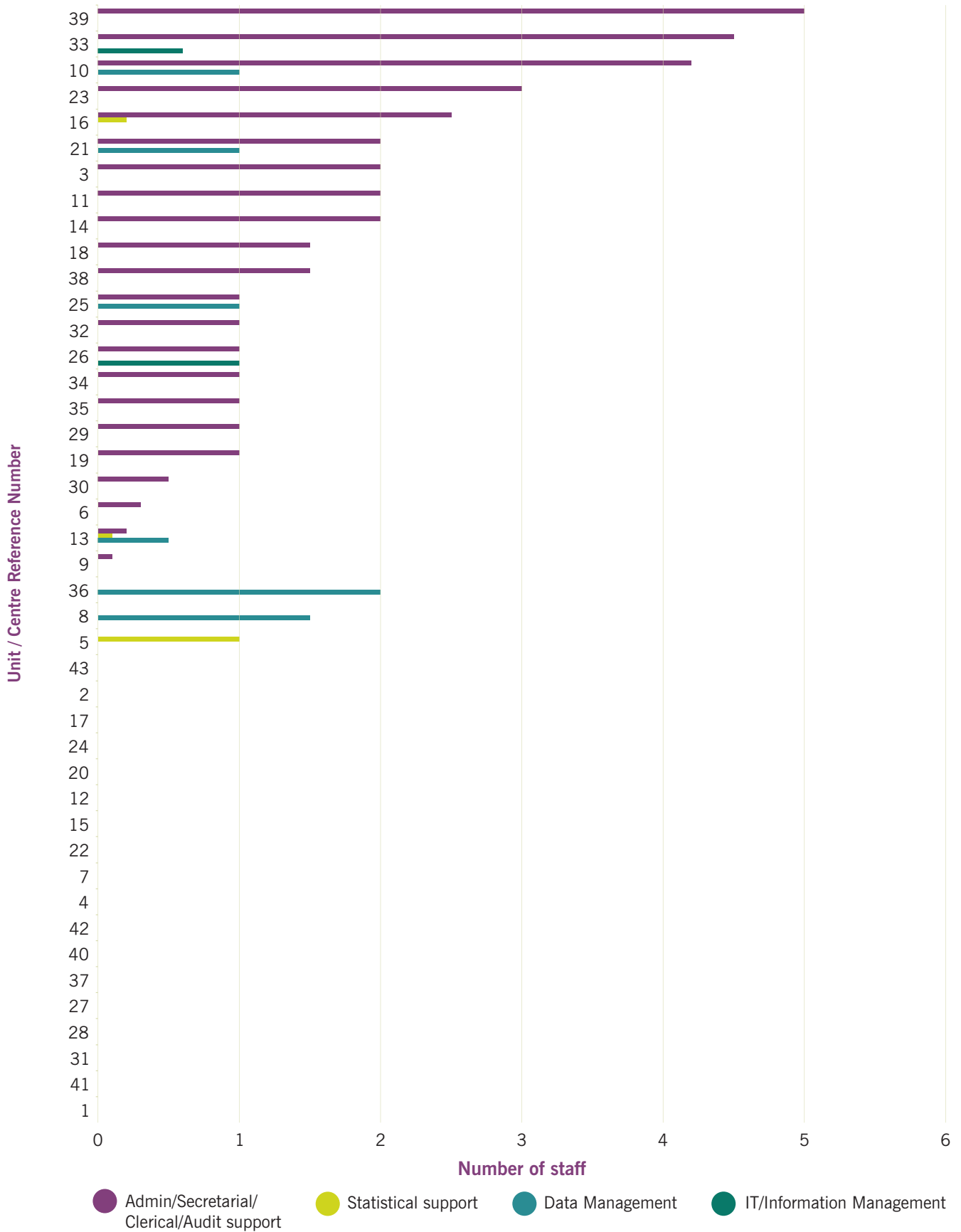


Figure A16 Total of FTE Research & Support Staff

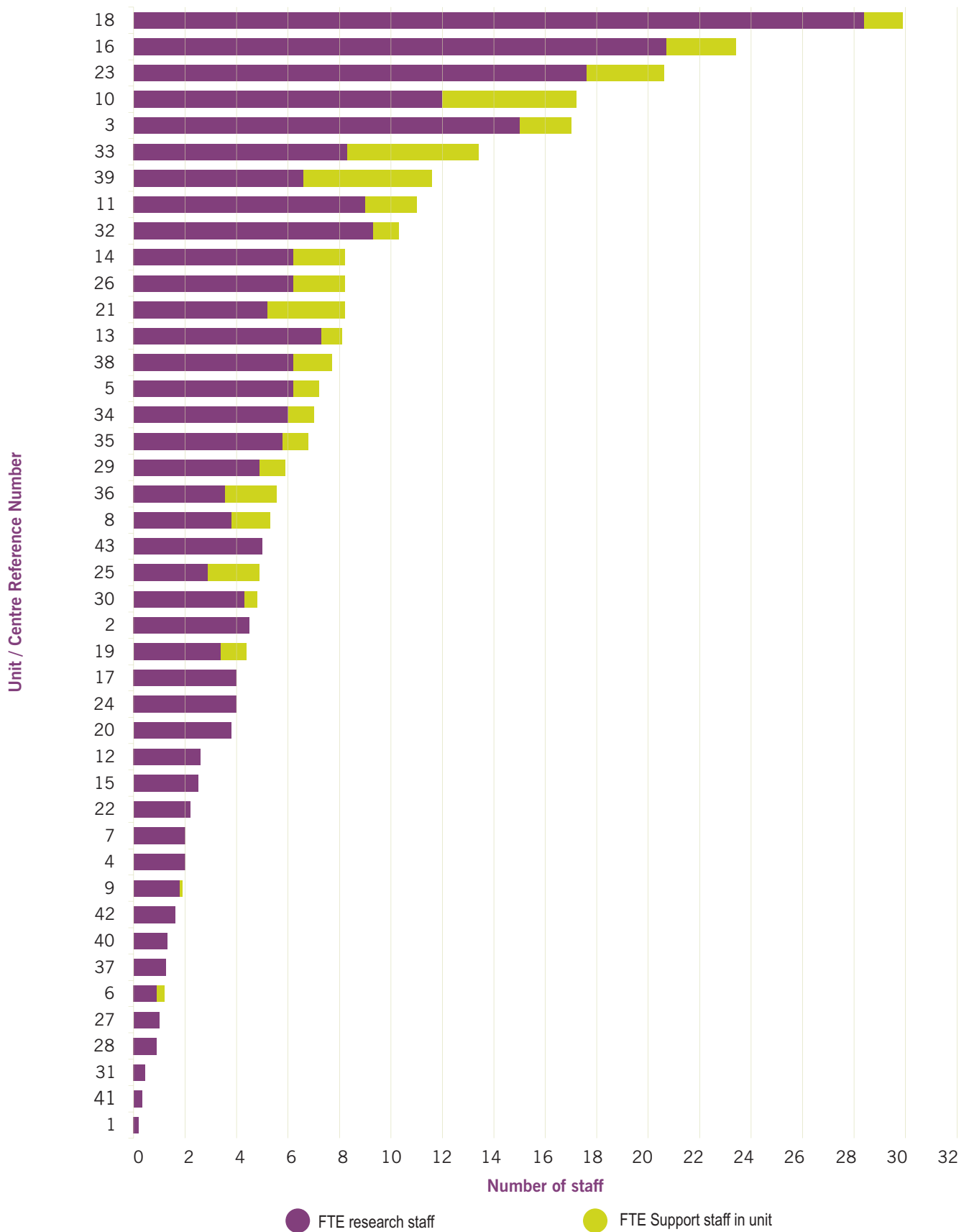
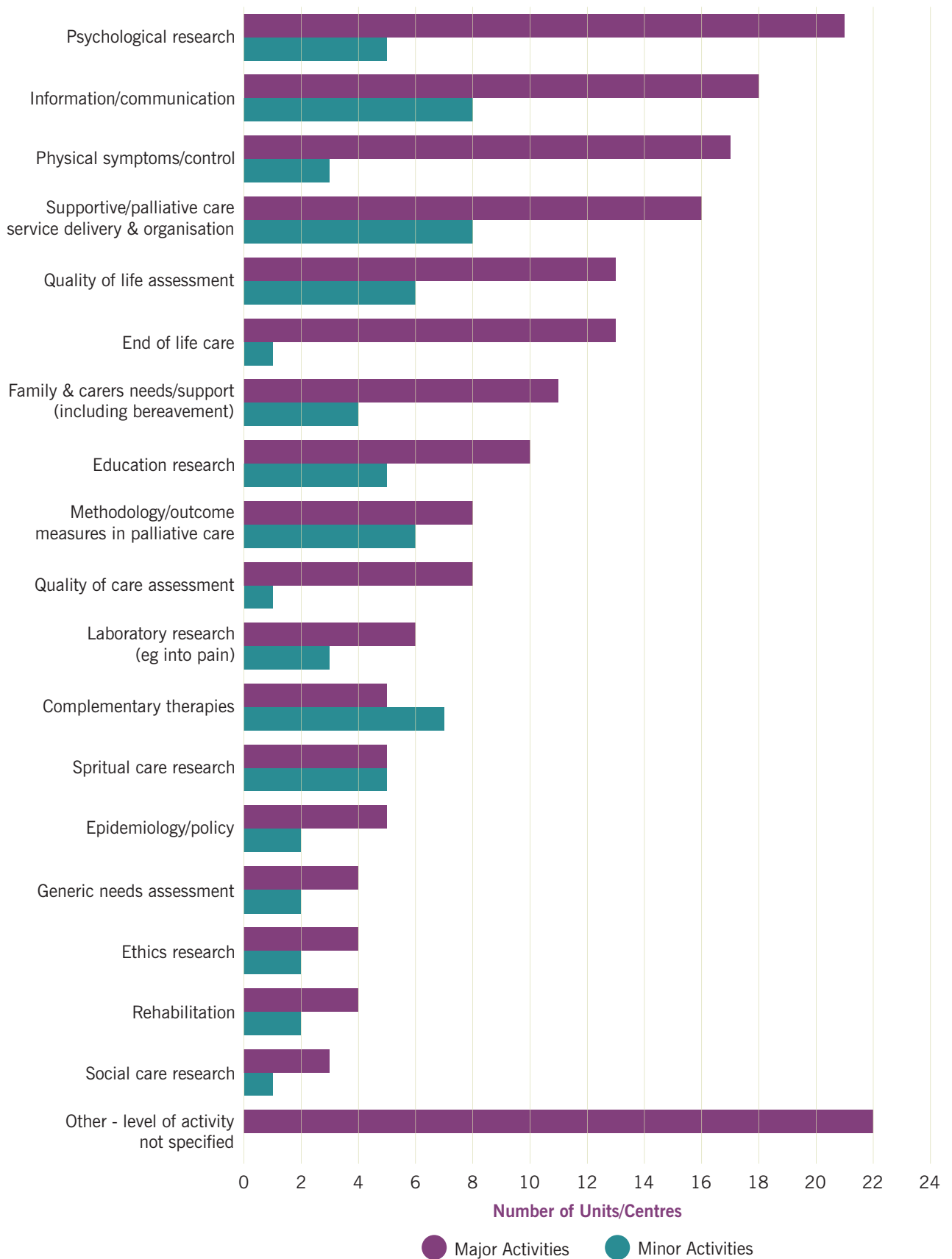


Figure A17 Research Topics



APPENDIX 3 ABBREVIATIONS

CASE	Co-operative Award in Science and Engineering
CRD	NCRI Cancer Research Database
CSDG	NCRI Clinical Studies Development Group
CSO	Common Scientific Outline
GPRF	MRC General Practice Research Framework
HEFCE	Higher Education Funding Council For England
NICE	National Institute for Clinical Excellence
OEDC	Economic Co-operation and Development
PIC	Potential Impact Category
R&D	Research and Development
RAE	Research Assessment Exercise
RL	Research Level
SCI	Science Citation Index
SPG	Strategic Planning Group
SSCI	Social Science Citation Index
SUPAC	Supportive and Palliative Care



**Association of the British
Pharmaceutical Industry**



**Marie Curie Cancer Care
(Marie Curie)**



**Association for International
Cancer Research (AICR)**



**Medical Research Council
(MRC)**



**Biotechnology and Biological
Sciences Research Council (BBSRC)**



**Northern Ireland Health & Personal
Social Services Research &
Development Office (N. Ireland)**



**Breakthrough Breast Cancer
(Breakthrough)**



**The Roy Castle Lung Cancer
Foundation (Roy Castle)**



**Breast Cancer Campaign
(BCC)**



**Scottish Executive Health
Department (Scotland)**



**Cancer Research UK
(CR-UK)**



**Tenovus The Cancer Charity
(Tenovus)**



**Department of Health
(DOH)**



**Wales Office of Research &
Development for Health & Social
Care The National Assembly for
Wales (Wales)**

Llywodraeth Cynulliad Cymru
Welsh Assembly Government



**Leukaemia Research Fund
(LRF)**



**The Wellcome Trust
(Wellcome)**



**Ludwig Institute for
Cancer Research (Ludwig)**



**Yorkshire Cancer Research
(YCR)**



**Macmillan Cancer Relief
(Macmillan)**

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