Physical activity in asthma patients

A key trial in lymphoma treatment

Nursing and Midwifery Revalidation

Diverse Sex Development

Lih-Mei Liao on approaching the field of DSD as an academic-clinical psychologist

Celebrating our staff’s achievements

Master’s in Clinical Research and Training Fellowships

In collaboration with CNMR
Centre for Nurse and Midwife Led Research
At UCLH, we have a strong vision that drives all we do and is clearly linked to our joint Nursing, Midwifery, AHP and Pharmacy strategy. This strategy recognises the unique contribution our professions make and the launch of Connect shows how we can continue to inspire, innovate and generate world-class research.

It has been my ambition to create a positive culture that supports professionally-led research, building capability and capacity in research skills to deliver top-quality patient care by using best evidence to improve outcomes and advance practice. Reading the submissions for our first issue reminds me just how amazing our staff are. I hope you will enjoy reading it as much as I have.

Finally, a special thank you to our editorial team and CNMR for their continual support.
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Physical activity in a severe asthma population

H. Bellas, R. Livingston, J. Sahota, T. Bidder, D. Robinson

Introduction
In 2009, only 40% of men and 28% of women met NICE recommendations for physical activity (PA) in England. The health benefits of PA are significant and well-recognised, but the consequences of physical inactivity have not been investigated in asthma. A systematic review hypothesised that breathlessness, asthma control and the fear of physical exertion triggering symptoms were barriers to PA.

Aims and objectives
To determine PA levels in a Severe Asthma (SA) population and identify reported barriers to exercise.

Method
Patients assessed by a SA Service completed the General Practise Physical Activity Questionnaire (GPPAQ), a NICE-recommended 4-level PA index tool, and a six-minute walk test (6MWT). Reported barriers to exercise were grouped into categories for analysis.

Results

<table>
<thead>
<tr>
<th>Table 1. Study of PA levels in SA population</th>
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</thead>
<tbody>
<tr>
<td>Total number of patients</td>
</tr>
<tr>
<td>Median age</td>
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<tr>
<td>Median FEV1</td>
</tr>
<tr>
<td>Median BMI</td>
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<tr>
<td>Median 6MWT result</td>
</tr>
<tr>
<td>Percentage meeting NICE recommended PA levels</td>
</tr>
<tr>
<td>Those reporting asthma symptoms as barrier to PA</td>
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</tbody>
</table>

The benefits of PA are significant but the consequences of physical inactivity have not been investigated in asthma.

Figure 1. Pie charts to show percentage of population meeting NICE-recommended physical activity (PA) levels

General population*  
66%  
34%  
Severe Asthma population (study)  
82%  
12%

* Source: NICE

The most frequently reported barrier to PA in the group was asthma symptoms.

Conclusions
PA levels in a SA cohort are markedly reduced. In contrast to the general population, leisure time and work commitments were not the main reported barrier, but rather asthma symptoms. This highlights the need for specialist multidisciplinary intervention in SA. The effect of a PA intervention in this population needs to be further investigated.
Is it a boy or a girl? This question is often the first to be asked of midwives and obstetricians by new parents, who expect the answer to be one or the other. The taken-for-granted dimorphic sex categories of male and female obscure the fact that the embryonic tissues that develop into testes, penis and scrotum are initially the same as those that develop into ovaries, womb, vagina, clitoris and labia. Sex differentiation typically begins at about six weeks of embryonic life, and a hitherto undifferentiated foetus soon assumes the anatomical structures and appearance of what we think of as female or male.

Little is known about the genetic conditions that alter the developmental pathway so that the usual markers of sex – gonads, genitalia and karyotype are neither female- nor male-typical. Prevalence depends on inclusion criteria. Using a very broad definition, prevalence of live births associated with atypical sex characteristics, ranging from mild to obvious, has been estimated to be as high as one in two hundred, although each of the numerous named conditions is far rarer.

The past two decades have witnessed rapid advances in molecular biotechnology that have resulted in the identification of more variants of what are often called intersex conditions, so a different categorisation scheme was needed to facilitate the burgeoning basic science research. In 2006, the intersex nomenclature underwent major revision and development in the (first international) ‘Consensus Statement on the Management of Intersex Disorders’. The term ‘disorder of sex development’ was invented to encompass all ‘congenital conditions in which the development of chromosomal, gonadal or anatomical sex is atypical’. Genetic diagnosis has begun to replace clinical diagnosis as the gold standard.

“Sex differentiation typically begins at about six weeks of embryonic life, and a foetus soon assumes the anatomical structures and appearance of what we think of as female or male.”
or adulthood, sometimes alongside other bodily differences and/or medical problems. Medical management of problems that threaten immediate or long-term health is not questioned, but genital surgery to ‘normalise’ appearance and function of the sex anatomy is.

Sexual outcomes of normalising genital surgery by definition can only be examined longitudinally, when the children who have been operated on reach puberty and adulthood, i.e. many years after the procedures are initially performed. Persistent concerns expressed by adults who have been recipients of childhood genital surgery have prompted clinicians at UCLH to recall adults previously lost to paediatric follow-up. In a landmark study, 44 adolescent girls with a DSD condition called congenital adrenal hyperplasia (CAH) who had undergone normalising genital surgery in childhood were reviewed by Sarah Creighton and her team at UCLH. Despite multiple childhood operations, nearly all of the study participants had required further surgery for menstrual flow or vaginal intercourse or both in adolescence and adulthood. These findings raised issues about how accurately informed the consenting parents were.

“It is undeniable that there is a groundswell of provider and recipient opinions that interrogate the practice of normalising genital surgery on children who cannot give consent.”

From about the early 2000s, formal acknowledgment of the need for integrated care from a multidisciplinary team (MDT), including access to psychological input, can be identified in almost all clinical recommendations. However, how should psychological clinicians define and implement psychological input in DSD medicine? I argue that it is crucial to be both investigator and clinician in this highly-privileged endeavour and any other new area of clinical practice. The particular blend of academic skills and clinical experience is what has enabled me to read the literature critically and accept a perpetual curiosity and need to make discoveries and improvements. The following is a summary of what I currently consider to be key tasks for psychological practitioners working in DSD in the UK. My research output has helped to ensure that at least some of these ideas are taken seriously.

**Psychological contributions via research**
The psychological dimension of the research has enabled us to identify that women who have had childhood genital surgery reported more difficulties with orgasm. It helped to demonstrate that genital sensitivity is diminished at the site of surgery. Our team research output was initially celebrated by affected adults whose dissatisfaction had hitherto been dismissed by the medical community. In time, researchers from different parts of the world became more willing to question the surgical focus in DSD care. The quality of the flurry of more recent reports on the long-term outcome of cosmetic genital surgery is variable, but it is undeniable that there is a groundswell of provider and recipient opinions that interrogate the practice of normalising genital surgery on children who cannot give consent.

**Emotional safety for patients and families**
Academic training is required to critique and interpret research. My research was built on a critical reading of the psychosocial analyses thus far and the narratives published by affected adults and parents. The works point to a significant risk of psychological harm in DSD. Uncontained emotional distress may render it difficult for parents to prioritise the child’s future in their desperate attempt to normalise their child. Poor emotional care compromises the principles of informed consent.
Throughout their lifespan, people with atypical sex anatomies may be overly medicalised. As their genotypes and phenotypes fascinate clinicians and researchers, intimate examination and medical photography have not always been optimally-managed. Furthermore, medical eagerness to correct what is deemed an aberration could set off a negative chain reaction in how the affected person is perceived and how distressing it may be for the people who care about them.

An important role for psychosocial professionals is to facilitate team reflections, to prioritise emotional containment for affected persons rather than cosmetic interventions and to help to mitigate the significant communication barriers imposed by the binary language on sex and gender.

Managing stigma

Stigma is defined as a negative sense of social difference from others or as an adverse reaction to the perception of a negatively-evaluated difference. This ‘difference’ is outside of the socially-defined norm and therefore deeply discrediting. Fear of devaluation can be part of the psychological landscape of many affected people. Research participants have also spoken of feeling like outsiders unentitled to relationships. Supported exploration of feelings of stigmatisation is perhaps the most important focus in psychosocial interventions. Stigma, shame and avoidance often surface in dilemmatic decisions on self-disclosure about DSD in social situations. Openness is generally felt to be high-risk (for example, ‘people would flip if they find out’), whilst withholding information may be experienced as a moral lack of personal integrity (for example, ‘what kind of person does my secrecy make me?’).

Whereas a person can choose not to disclose in many situations, given the presence of physical signs, choosing not to disclose to sexual partners is more difficult. Some individuals may withdraw from intimate relations in order to avoid having to explain. Avoidance and safety-seeking, despite a desire for relationships and intimacy, can persist for years. Distress may be expressed in seeking (further) surgery to afford ‘normality’ in identity, relationships and sexual practices, even though expressions of happiness and joy appear to be far more identifiable in the narratives of people who embrace their differences and engage with like-minded people.

Reconsidering gender

The belief that all genitals look discretely male or female and that they are not only capable of but are naturally inclined towards blissful union with each other seldom comes into question in our society. The normalisation/naturalisation of genital intercourse frames a wide range of pleasurable and meaningful sexual experiences as ‘other’ and vastly limits the construction of these experiences as satisfying and affirming.

My research has identified a high prevalence of anticipatory and experienced sexual difficulties regardless of diagnosis and whether or not women have undergone genital surgery. In psychosexual education and support, I have, based on this and other psychosocial research, advocated a move away from ‘normal sex’ and a greater emphasis on sensuality rather than gender performance. I believe this shift can afford more scope for my patients to experience sexual pleasure as they become more open to opportunities for good-enough sexual enjoyment and relations.
Some of these ideas have been taken up in the development of a vagina dilation protocol at UCLH as a less invasive alternative to surgery. This protocol is currently being jointly implemented by psychologist Caroline Finill and nurse specialist Louise Williams.

**Facilitating informed choice**

DSD does not preclude people from living well. However, the diagnosis could propel individuals into dilemmatic decisions. Psychologists are especially aware of the fact that many treatment decisions are more emotion-based than we would like to acknowledge. For some patients, life with DSD may be punctuated by dilemmatic decision-making.

In infancy and early childhood, parents may be presented with the option of normalising genital surgery. As it does not affect the child’s health, DSD teams should ensure that it is presented as a choice, and give weight to non-intervention as an equally valid choice. Parents should be allowed plenty of time to recover from the shock of the diagnosis, digest all of the information, consult with support groups if they wish and, most importantly, bond with their child. When parents decide on normalising surgery, they are likely to be seeking ‘normality’ for their children in future identity, sexuality and relationships. Psychosocial professionals can gently guide parents to question what is normal in identity, sexuality and relationships. They can help parents to weigh up the reality of the surgical trajectory, which may involve repeat operations and examinations, and uncertainties about the anatomical and psychological impact. For the currently small proportion of parents who decide to defer surgery until their child can give consent, psychological input may need to be intensified to co-create the best approach to educate and support the affected child, the siblings, the extended family and perhaps the wider community.

Choice is important not just for surgery. Studies with other populations suggest that genetic testing could pose significant dilemmas for family members who may struggle to discuss certain conditions and carrier status. The Androgen Insensitivity Syndrome Support Group in the United Kingdom, [www.aissg.org](http://www.aissg.org), has documented how genetic testing could fill people with dread about having to discuss DSD within the family. A collaborative approach means plenty of time and opportunity to help people explore the potential implications of genetic testing for family relationships, as well as education and support for potential carriers to consider the implications (including the communication challenges with the next generation).

This leads to the issue of supporting individuals and couples in their parenthood considerations. Choosing to be childfree is entirely valid for all individuals and couples, whether with or without a DSD diagnosis. For those who wish to be parents, adoption is a viable option across all diagnostic groups. Consumption of assisted reproductive technology is characterised by uncertainties and dilemmas that can stretch coping capacity. Complex treatment with uncertain timings and outcomes should not be presented as a straightforward solution for a desire or longing to reproduce, however understandable. Rather, many individuals and couples need psychological input to manage expectations and emotions and to maintain a healthy engagement with the broadest possible range of life goals.

**Conclusion**

DSD encompasses numerous congenital conditions associated with atypical development of chromosomal, gonadal or anatomical sex. Traditional medical management has been dominated by a surgical focus and longitudinal evaluation has been sparse. Reservations from adults where the condition has been surgically managed in childhood and recent research...
with adults have prompted a re-examination of the approach. A shift from a surgical to a multidisciplinary focus is evident, and integral psychological care is emphasised. The change in ethos has opened up more possibilities for psychosocial professionals to contribute to debates and solutions relating to diversity in sex and gender.

My contributions to the field as a psychologist have been largely dependent on my training as an investigator as well as a clinician and on the good fortune of working with progressive academic medical practitioners at UCLH. What if I had been a jobbing nine-to-five psychologist? This is a question I cannot answer. One possibility is that I might have leant on the safety of conventional psychological practice and treatment of mental health problems. That would mean missing the opportunity of developing new insights into the dilemmas of affected individuals and their families and care teams, and the chance to encourage DSD professionals to reflect on the limits of medically shoeorning people born different to fit with a narrow definition of normal.

A note about the author
Leh-Mei joined forces with Sarah Creighton and Gerry Conway in the late 1990s when a patient advocacy group pursued them to form a multidisciplinary team (MDT) for adults at UCLH. Over the last 15 years she has deployed her training in investigation to make sense of what she observed clinically. This team has since expanded, with adolescent urologist Dan Wood and fertility expert Ephia Yasmin joining. Together, their interdisciplinary research has posed significant challenges to traditional medical management.

Select interdisciplinary publications
Caring for people with long-term neurological conditions/spasticity
A quality review of a Specialist Multidisciplinary Service

Elizabeth Keenan (Project team lead) elizabeth.keenan@uclh.nhs.uk
Project team: Katrina Buchanan, Dr Val Stevenson, Dr Rachel Farrell, Heesook Lee, Dr Gerry Christofi, Honey Padilla, Laura Bullass, Becky Jones

Keywords Spasticity, multi-disciplinary, intrathecal baclofen, reflection, emotional touchpoints

The project was completed in association with the Foundation of Nursing Studies (FoNS) and the Burdett Trust for Nursing

Introduction to spasticity management
The project lead works at the National Hospital for Neurology and Neurosurgery (NHNN) in a specialist multidisciplinary spasticity team. This multidisciplinary spasticity management team provides local and national care for patients with chronic long-term conditions and specialist care for ‘People with Spasticity’ (PWS). If admitted, patients come to the rehabilitation unit where a team of nurses are familiar with caring for people with these complex needs. There are many elements to care management for those with severe spasticity. An intrathecal baclofen (ITB) pump is one option that can be life changing and is used when oral spasticity medications are ineffective or cause too many side effects for patients. An ITB pump is a programmable device that is surgically implanted into the abdomen. It has a catheter attached that is tunnelled under the skin around the lumbar spine where it sits in the intrathecal space, delivering the prescribed baclofen medication into the cerebral spinal fluid. It is implanted under general anaesthetic and patients have two wounds, one in the abdomen and one in the lumbar spine. Patients and their carers receive information, education and support on all aspects of the ITB pump function and their ongoing care while at the hospital.

Project overview
The project lead, in conjunction with the multidisciplinary team, wanted to understand the impact that the intrathecal baclofen pump has on the quality of life of patients and their carers. It was hoped that this would also result in collaborative working with patients to agree how education and support can best be provided to patients themselves, and their carers or families, who are living with an ITB pump in the future. To support this work, a successful application was made to the Patients First Programme at the Foundation of Nursing Studies (FoNS). The FoNS Patient First

“The project lead, in conjunction with the multidisciplinary team, wanted to understand the impact that the intrathecal baclofen pump has on the quality of life of patients and their carers.”
Programme fitted well with the service evaluation needed for the ITB service, as it provided the opportunity to:

• recognise the importance of taking time to look at the service
• explore and value the huge impact the service can have on people’s lives and the importance of applying this user experience within a service
• recognise how powerful patient stories are
• get feedback from the staff involved in caring for the patients.

The Patients First Programme provides the support of a dedicated experienced practice development facilitator, workshop days with other teams and a small bursary. Project teams also have full access to the FoNS library and website, the Centre for Nursing Innovation (www.fons.org). The programme was invaluable in providing practice development methods and approaches such as the values clarification exercise and the claims, concerns and issues exercise, which helped to engage the wider team and increased confidence in using the methods.

Aim and objectives
The aim of the project was to evaluate the impact of an ITB pump on the quality of life of people with spasticity and their carers. The objectives were to:

• engage key stakeholders in the project
• capture patient stories
• undertake a workshop with the ward nursing staff to gather and capture their involvement in the patient pathway
• understand how a practice development framework will help implement changes in practice for patients and carers
• plan how the patient and staff experiences will help co-design a more user-friendly service.

Methods and approaches
A mixed method approach was used including the following methods: emotional touchpoints (way of gathering patients’ experiences through images or words), patient and staff focus groups, and an on-line Survey Monkey questionnaire to inform and evaluate our current practice. We ended with a celebration event for patients, carers and staff.

“...A mixed-method approach was used, including emotional touchpoints, patient and staff focus groups, and an on-line questionnaire.”

Results
There were three main themes from the project:

• Education and adjustment – to the complex needs of the patient and ensuring the best care.
• Improving quality of life – this intervention may help give the patient hope for the future with less pain and better management of their unpredictable spasticity and spasm.
• Support for the patient once discharged – ensure follow-up is in place, that the community teams are aware and that the patient has the support from the spasticity team once discharged.

Conclusions and implications for practice
Service evaluation continues to be at the forefront of practice for the spasticity team at the NHNN and remains an ever-evolving model. Many of the objectives were achieved because the practice development tools engaged patients to open up and tell their unique stories. Stories are very powerful and feedback from the Rehabilitation in Multiple Sclerosis (RiMS) conference and the ITB Forum suggested that patient views are often overlooked, this needs to be addressed and considered in this service going forward. By raised awareness of ‘patient experience’ in our service, we have managed to start a user group that is invaluable to current users and people who are considering management of their spasticity with ITB.

This project gathered valuable information on the unique impact ITB can have on a group of patients. However, it did not accurately assess the impact for carers. Many of the practice development tools could be used to help capture the impact on carers and this needs further discussion. By presenting the service in a transparent way to patients and staff, the team can question current pathways, evaluating the educational support and allowing us to design change.
The many challenges encountered, such as moving ward and difficulties in setting up the staff workshops, were addressed with good teamwork and open ‘can-do’ discussions. It was apparent that the project created interest in all staff groups and patients, and a desire to get involved and engage in the process to help shape change for others in the future. People valued being asked and participating.

**Implications for practice:**

- Whilst it is useful to develop a shared purpose or goal, the nature of practice development is that it requires open-mindedness and flexibility as new ideas and directions might emerge.
- Moving from a directive to facilitative leadership involves the development of new skills and knowledge to use in practice.
- Emotional touch point cards may be useful as prompts for patients or staff to tell their own stories, giving a reminder of past feelings or as permission to express a variety of emotions.


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**Facilitating early diagnosis of breast cancer among Black and South Asian women in a London borough**

*Patricia Hughes, Matron, UCH Macmillan Cancer Centre (patricia.hughes@uclh.nhs.uk)*

**Introduction**

Black and South Asian women in the UK have a higher mortality rate from breast cancer than their white counterparts, one of the reasons for this is due to late-stage presentation of the disease. This has also been observed in the USA among African-American and American-Indian women.

A critical review of the current literature was undertaken to ascertain whether the early diagnosis of breast cancer could be facilitated in order to improve outcomes for Black and South Asian women in a London Borough.

"Black and South Asian women in the UK have a higher mortality rate from breast cancer than their white counterparts."

**Search strategy**

- Search terms of women, cancer and ethnicity combined.
- Search results combined yielded 353 of these titles and abstracts reviewed.
- 277 research studies excluded due to different cancer, ethnicity, theme, stage of cancer (exclusions included literature reviews, out-of-date range and repeated studies).
- Abstracts of the remaining 76 studies were reviewed for relevance to the research question.
- 10 research studies were finally selected and further analysed.

**Methods**

A critical literature review was undertaken. The databases searched were, CINAHL, ASSIA and MEDLINE. Studies that were conducted in the UK and USA were included and study quality
The study found there was a poor uptake of breast cancer screening among Black and South Asian women both in the UK and the USA.

Findings
The three main findings arising from the critical literature review were:
• a poor awareness of breast cancer
• a fear of breast cancer
• poor uptake of breast cancer screening among Black and South Asian women both in the UK and the USA.

Conclusion
The critical literature review demonstrated the complexities in regard to facilitating the early diagnosis of breast cancer for Black and South Asian women.

Recommendations and further research
Culturally competent care is fundamental as it has been observed that culture has a large influence on breast cancer awareness, fear of cancer and the uptake of screening. Furthermore, ensuring that information is culturally-tailored to enhance understanding is of paramount importance. Further research is needed to ascertain if this is helping to facilitate the early diagnosis of breast cancer for Black and South Asian women.

Limitations of the review
The literature review was undertaken by the author only, therefore it could have been subject to bias in the final selection of the research studies. For future critical reviews, the use of a peer reviewer would have enhanced the credibility of this study.

References
1. Bowen et al., 2008
2. Marquez-Margana et al., 2013; Ndukwe et al., 2013

Further references
My Masters in Clinical Research (MRes)

Research Nurse Laura Gallego and Physiotherapist Cat Lawrence discuss their MRes experiences and share a few top tips

Laura Gallego, Cat Lawrence

A Masters in Clinical Research (MRes) is available to non-medical NHS healthcare professionals. There are both HEE- and NIHR-funded studentships available which provide a unique opportunity for non-medics to have support to develop research skills with a specific focus on their area of clinical interest.

Laura Gallego is a research nurse in critical care and anaesthetics at UCLH, she graduated from an HE NCEL funded MRes programme in January 2017. Laura has recently completed a qualitative study looking at the attitudes towards pre-operative exercise of colorectal oncological patients. She recently presented her study as a poster at the RCN International Research Conference and is currently working towards publication.

Cat Lawrence, who is the team lead physiotherapist on critical care at UCLH, graduated from an NIHR funded MRes programme in January 2016. Cat conducted a quantitative study investigating the relationship between patient motivation and participation in physiotherapy on critical care. The study has been presented as a poster at a UK critical care conference and Cat is currently working towards publication. Below they both provide an insight into their experience of applying for and completing this award.

Laura
I feel privileged to have received one of the HE NCEL funded MRes fellowships. This has been a fantastic learning opportunity which has provided me with the knowledge and confidence to lead research clinically. It allowed me protected time to design and conduct a study based on my own research idea, supported by an experienced researcher at City University. This wasn’t an easy ride and required preparation and commitment.

Three years ago, I came across the available NIHR/HE NCEL funded MRes. To make myself a strong candidate for one of these funded places, I worked towards being published alongside other researchers, and tried to develop an interesting idea for my research proposal.

The proposal should be an original idea relevant to clinical practice but most importantly it must benefit patients. I would suggest to anyone interested in applying that they have conversations with colleagues about research topics at the earliest opportunity. For those with no research experience, the NIHR offers six-month internships working within an established research team.

Thinking about the application process, identifying a mentor was key to my success in obtaining the fellowship. This mentor selflessly helped me by proof-reading my application and practicing interviews. It is very important that your application stands out, so make sure you invest enough time in it. I was unsuccessful with my first two interviews but, after much perseverance, I was successful on my third attempt.

Towards the end of my MRes, I felt excited but nervous about utilising the information learnt during this last year. It turns out this is a common feeling amongst MRes students. However, I have now settled back into my previous role as a clinical research nurse in Peri-Operative Medicine. I now enjoy a large network of fellow nurse researchers, many of whom I came into contact with during my period of study and some of whom I have met since.

“ This has been a fantastic learning opportunity and provided me with the knowledge and confidence to lead research clinically.”
Cat
Throughout my career as a physiotherapist, remaining up-to-date with research has been an integral part of my role. Prior to the MRes, I was involved in local level projects including service evaluation, audit, and data collection. However, I often had more questions than answers and I was keen to build on the foundations of my current knowledge and take a more independent role in the topic of my research. After specialising in cardiorespiratory physiotherapy, I was keen to understand more about the process of implementing research in my specialist area of interest, critical care.

I was looking to challenge myself in a new area and the MRes course offered the perfect combination of research and education. The course offers the opportunity to develop specific research skills, for example, statistics, and critical appraisal through structured modules, whilst also giving the freedom to complete an independent research project.

I opted to complete the MRes full-time in 2014. It was a challenging experience but through the course I was able to work alongside like-minded professionals from a range of healthcare fields. This provided the chance to see things from different viewpoints and develop a network of colleagues, many of whom I am still in contact with. My research idea developed and changed throughout the MRes but by the end of the course, and with the support of colleagues and experienced researchers, I had completed my own NHS research study.

The MRes Programme provided an excellent opportunity to develop greater knowledge of the research process whilst also allowing me to explore new ideas and contribute to current thinking. Similarly to Laura, I was apprehensive about returning to clinical practice and unsure of what direction my career would take. It took time to adjust back into clinical work, but I have settled and I am eager to help my colleagues embed research into everyday practice and hopefully take the next steps towards a career as a clinical researcher.

**MRes top tips**
- The list of current Universities offering funded places can be found on the NIHR website www.nihr.ac.uk/funding-and-support/funding-for-training-and-career-development/training-programmes/nihr-hee-ica-programme-irmes.htm
- Attend available open days for each University to establish if the course would be right for you and to get an idea of what they are looking for in applicants.
- Review and understand the research themes for the University you are applying to, this can prove helpful when preparing for the interview.

New publications
Recently published UCLH staff include Yana Richens in March’s *BJM*, and Elizabeth Sampson and Daniel Davis who were among the co-authors of a dementia and delirium essay.

**Cerebrospinal fluid shunts in the maternity context**

**Challenges and opportunities in understanding dementia and delirium in the acute hospital** (available at www.plos.org)
Thomas A. Jackson, John R. F. Gladman, Rowan H. Harwood, Alasdair M. J. MacLullich, Elizabeth L. Sampson, Bart Sheehan, Daniel H. J. Davis
Nursing and Midwifery Revalidation

A service evaluation of nurses’ and midwives’ experience at UCLH – a CNMR Journal paper

A. Finch, B. Clarence-Smith, C. Walsh, E. Kuria

Please note the content of this paper was presented in poster format at this year’s CNMR conference. An adapted version is also being prepared for publication in the Journal of Nursing Management.

Introduction
Since 1st April 2016, nurses and midwives have been required to revalidate as part of renewing their place on the Nursing and Midwifery Council (NMC) register. Revalidation is a professional requirement for all 692,000 qualified nurses and midwives in the United Kingdom. Revalidation helps those registered with the NMC demonstrate that they practice thoughtfully and professionally, and it supports commitment to ongoing professional development.

At UCLH, a Revalidation lead was appointed in August 2015 to help support staff across the organisation meet the new requirements. Intrinsic to this work was a desire to create and foster a culture of inquiry and reflection where opportunities to learn from everyday experiences would be encouraged – the antithesis of viewing Revalidation as a tick-box process. Nineteen ‘Revalidation champion’ volunteers were recruited from across UCLH to support this philosophy in practice.

To date, around 890 of the Trust’s nurses and midwives have completed a Revalidation application at UCLH, representing around a third of our NMC registered nurse workforce. All those consulted accessed the resources available within the Trust alongside the NMC website. This paper presents the key findings of a service evaluation that was undertaken amongst a cohort of our staff.

Methods
An evaluation of the experiences of nurses and midwives who have either completed a Revalidation submission or have acted as a reflective discussion partner or confirmer was undertaken between August and October 2016. The evaluation adopted appreciative inquiry¹ as its primary methodology to explore staff experiences. Appreciative inquiry focuses on what is going well in a system or process in order to identify what can be leveraged to have even greater impact, and, in this case, to also guide the focus of future Revalidation work. The evaluation placed particular emphasis on learning derived from individual’s practice-related feedback and reflection.
The methodology included data from a variety of sources: written feedback from the Revalidation through Reflection workshop (179 respondents), results of a survey sent to all staff who had completed Revalidation between April and August 2016 (70 respondents), champion meeting discussion, and themes from a focus group held in October 2016 with a diverse group of 16 staff. The results of the first three activities were used to develop the framework for the focus group questions and discussion.

The focus group conversation was captured by two note-takers, and the content underwent thematic analysis by the Revalidation lead. Two nurse ‘champion’ colleagues completed their own independent thematic analysis. The resulting themes were debated amongst the three individuals to generate a ‘master’ group of themes, which were then shown to a small group of staff to assess representativeness and resonance with their own experience. The resulting themes presented in Table 1 capture and describe how Revalidation has been experienced by participating staff, and how it impacts on their sense of professionalism and continuing development.

**Findings**

Since its launch in April 2016, around 890 nurses and midwives at UCLH have submitted Revalidation applications to the NMC. All applications have, to our knowledge, been accepted. This evaluation perhaps uniquely offers qualitative information on staff engagement with the Revalidation process, informing a sense of their commitment to the NMC requirement. Most significantly, the service evaluation suggests Revalidation has helped nurses appreciate and reconnect with learning from everyday experiences. “Revalidation makes you redefine what you do every day and enhances professionalism” asserts Jane Kimani, Staff Nurse and focus group participant. The emphasis, according to many individuals, is looking deeper at what you do already, rather than being asked to do more. Many describe their ‘Revalidation journey’ as fulfilling in a way that surprised them.

This finding has been described by staff of differing seniority and age. Amongst those who consider themselves ‘older’ or approaching retirement age, Revalidation has been referred to as ‘validating’ their nursing or midwifery experience in a way that builds self-worth. Intrinsic to the thematic findings is a sense of reconnection with what it means to be a professional. “Revalidation creates an opportunity to look at professional practice with a wider lens,” asserts Dillys Wright, CNS at the National Hospital for Neurology and Neurosurgery. Nurses and midwives describe being able to identify more closely with the NMC Code (2015) and feel that, through Revalidation, they have become more reflective. Table 1 presents the resulting themes, derived through analysis of the mixed qualitative data:

**Table 1. Revalidation: the experiences of nurses and midwives at UCLH**

- **Achievable**: it values what you do and encourages you to learn from these experiences, rather than expecting you to do more.
- **Personalised**: the process allows an individualised approach. Our reflective discussion is a personalised experience.
- **What we do every day is of importance.**
- **Our learning is derived from our experiences.**
- **Appreciative of our contribution**: builds resilience and pride and protects against burn-out.
- **Enhances a sense of professionalism**
- **Helps inform leadership** of individuals in the team; builds aspiration and commitment, supports personalised development plans and dialogue around what’s important to the individual.
- **Links the Code** more closely to our practice, with opportunities to strengthen and embed this further.

An emerging ‘Revalidation culture’ has been seen, with a largely positive response to the NMC requirements. The requirement to evidence more reflective practice appears to be perceived of particular value. The theme of ‘everyday learning’ featured prominently within the focus group part of the appreciative inquiry. Figure 1 over the page details the shift in this perception, seen both before and after participation in a Revalidation workshop and collated from participant feedback.
"I have been a registered nurse for many years, and I was surprised how much I learnt during the process of reflection and especially during the reflective discussion" described Bridget Clarence Smith, CNS. She went on to say "I felt recognised and empowered by this, and able to think clearly about my skills and how I can continue to develop". Focusing on the reflective element of Revalidation is one of the key implications for practice.

Implications
Revalidation at UCLH is being experienced as more than a process to work through, staff are seen to have actively participated in its true intent. The thematic findings both collectively and individually offer direction for future Revalidation work, with the aim of further supporting emotionally-intelligent and thoughtful patient care. Revalidation does link the Code to practice and there are opportunities to strengthen this further from the perspective of exploring what it means to be a professional.

One of the unexpected benefits of Revalidation is the appreciative nature of the preparation work. Developing a portfolio of evidence and then engaging in reflective discussion feels personalised and appreciative of an individual’s contribution to care. If Revalidation is seen by leaders as a ‘tool’ to support the development of staff and is facilitated well, it helps develop a sense of feeling “cared about” and “invested in” which may contribute to happiness at work and the retention of staff. Positioning Revalidation outside of other Trust processes keeps the engagement personal and has been seen to help in this regard.

The themes offer the organisation learning that can be built into Trust guidance and help steer where future support should be placed. Reconnecting with reflective practice in a semi-formal way is gaining importance and has been found to be of help and benefit to staff. Building on this, alongside promotion of practice-related feedback (gaining new insight into how others’ experience us), feels an intrinsic part of future work.

Conclusion
An appreciative inquiry model of evaluation has helped elicit the qualitative impact of Revalidation. It describes an emerging culture, within which nurses and midwives continually seek opportunities for practice feedback, reflect on everyday experiences and tangibly link their learning to their ongoing professional development. Revalidation for many nurses and midwives has been an affirming and endorsing experience, ‘validating’ to themselves their commitment to their profession and to the public.

Revalidation for many nurses and midwives has been an affirming and endorsing experience, ‘validating’ to themselves their commitment to their profession and to the public.

References

Further references


Lymphoma is a broad term for a number of malignancies derived from lymphocytes. Lymphoma is split into two broad categories, Hodgkin lymphoma and Non-Hodgkin lymphoma (NHL). Hodgkin lymphomas contain Reed Sternberg type cells, NHL doesn’t contain this cell type and is typically harder to treat. Patients are treated with chemotherapy and antibody therapy, failure of these therapies however is common. Many patients fail to get into remission with further chemotherapy. There is therefore a need for effective treatment strategies in patients who fail traditional treatment or who are unable to tolerate further chemotherapy and a stem cell transplant.

Over the past 20 years, monoclonal antibody therapy has revolutionised cancer therapy. Numerous antibodies that bind specific antigens on cancer cells have been made. Rituximab is one such example, this targets and binds an antigen called ‘cluster of differentiation’ (CD20) and has been used for many years to treat lymphomas with great success.

Epratuzumab has been developed by immunomedics and is currently under investigation for a number of conditions. This binds an antigen on lymphoma cells called CD22. CD22 is a transmembrane glycoprotein found on the surface of most B cells. Epratuzumab modulates B-cell function, survival and death. It has been shown to be a promising agent for lymphoma patients who failed rituximab therapy and chemotherapy.

“Over the past 20 years, monoclonal antibody therapy has revolutionised cancer therapy. Rituximab is one such example and has been used for many years to treat lymphomas with great success.”

Chemotherapy has a high failure rate as treatment for NHL patients. This study is primarily designed to determine the safety, tolerability and MTD of BAY17854.

After binding to the CD22, antigen epratuzumab is rapidly internalised into the cell. This has led to the development of epratuzumab linked to a radionuclide, a molecule which emits energy in the form of alpha radiation. Immunomedics are collaborating with Bayer who has developed a thorium-227 payload, this emits alpha particles and together they have developed BAY17845 – epratuzumab linked to thorium-227, a novel radioimmunotherapy.

Alpha particles are able to penetrate a few cell lengths in the body, releasing their energy over a short distance. This means they will induce DNA damage, which will be lethal for the cancer cells. Their effect on other cells in the body will be minimal as the drug is concentrated in the tumour. This represents highly-targeted radiotherapy with minimal side effects.

In 2015, the Royal Free Hospital and UCLH were approached by Bayer to run a first-in-man clinical trial of BAY17845, epratuzumab conjugated to thorium-227, for NHL patients who had failed standard first-line treatment. This trial is a 3 x 3 dose escalation study designed to find the maximum...
tolerated dose (MTD) of BAY17845. Three patients are recruited to a predefined low dose of the study drug. If this is deemed to be safe, three more patients are recruited at a higher dose level. This repeats for six dose cohorts or until a dose-limiting toxicity is found (DLT). If a DLT is found, that dose cohort is expanded to six patients. If, out of those six, no more than one DLT is found the study then moves on to the next dose cohort. If two or more patients experience a DLT in a cohort size of three or six, the study will stop and the preceding dose cohort will be declared as the MTD.

BAY17845 is given as an intravenous injection. The study is primarily designed to determine the safety, tolerability and MTD of BAY17845. Other objectives include: obtaining data on the drug’s biodistribution, radiation dosimetry and pharmacokinetics, and exploring biomarkers and tumour responses.

The UCLH haematology service is collaborating with the Royal Free Hospital (RFH) to run this trial. Patients are approached and prepared for the trial at UCLH. Preparation of BAY17845 takes place at the RFH pharmacy where patients are dosed and then followed-up in the lymphoma clinic at the UCLH Macmillan Cancer Centre. Patients receive a dose of BAY17845 every six weeks and can have up to four injections. Working across two trusts has been a logistical challenge for staff at both hospitals along with Bayer. The day of dosing is particularly busy...The two sites have come together to form an effective team.

"Working across two trusts has been a logistical challenge for staff at both hospitals along with Bayer. The day of dosing is particularly busy...The two sites have come together to form an effective team."
In 2016, the Centre for Nurse and Midwife Led Research (CNMR) released a call for their inaugural Nursing, Midwifery and Allied Health Professional (NMAHP) research training fellowships. These fellowships are aimed at supporting NMAHPs at UCLH to develop competitive applications to obtain further research funding, such as NIHR Masters in research, doctoral or post-doctoral research fellowship grants. Funding streams such as these are fiercely competitive and applicants for doctoral and post-doctoral award schemes are often advised to set aside a number of months, even up to a year, to design their research plan and build their proposed support team. The CNMR research training fellowship offers a unique chance to take dedicated time, set aside from busy clinical jobs, to allow NMAHPs within the Trust who are interested in research to gain a first step on the ladder to becoming clinical academics.

As a rotational physiotherapist in University College Hospital, I was fortunate to have had a secondment opportunity to assist with running a cancer survivorship and exercise trial and enjoyed 18 months immersed in a research environment. During that time, I recognised that there were gaps among the impressive medical research and clinical trials being conducted at UCLH, particularly in my field of interest, cancer survivorship and lifestyle. These are areas of research that could be led by nurses and allied health professionals. I knew that I wanted to pursue a clinical academic career path and I made my first application for NIHR PhD funding but, unfortunately, it was unsuccessful. Despite having received excellent feedback on my application from the NIHR, my return soon after to a full-time clinical post made it difficult to devote the time required to improve my application in order to reapply the following year and my research proposal was temporarily shelved.

The CNMR fellowship scheme came at just the right time for me and, after an application and interview, I was awarded one of the first of the amazing CNMR fellowship opportunities.

My fellowship granted me six months of 0.4 whole time equivalent (two days a week), dedicated research activity time and my department received the equivalent funds to provide backfill for my clinical post. My proposed academic department, the Department of Behavioural Science and Health at UCL, have provided a work space and superb support within an academic environment and I can focus on my research activity away from the distractions of the clinical department.

Another excellent benefit of the CNMR fellowships is the chance to meet on a monthly basis with the other NMAHP fellows. These meetings allow discussion on research topics pertinent to our grant applications, such as patient and public involvement (PPI) and publishing papers, as well as offering much-needed peer support during the varying
Activities during this fellowship included attending workshops on PPI, meetings with research design service, joint research office and PPI advisors, leading on and contributing to academic papers, assisting with proposals for other funding grants, and attending and presenting a poster at the CNMR conference.

Dr Lih-Mei Liao, a senior clinical-academic health psychologist, has facilitated these sessions and provided mentorship throughout the fellowship.

Dedicated time, an engaging environment and regular support enabled by the CNMR fellowship allowed me to fully review and resubmit a doctorate fellowship application to the NIHR in January. Activities that I could afford to do during this fellowship, which will hopefully strengthen my esteem and potential as a future clinical academic as well as my funding application, included attending workshops on PPI, meetings with research design service, joint research office and PPI advisors, leading on and contributing to academic papers, assisting with proposals for other funding grants, and attending and presenting a poster at the CNMR conference in February. I am currently preparing a second bid for doctorate funding through the HEE/NIHR Integrated Clinical Academic Programme, which will coincide with the conclusion of my CNMR research training fellowship in May.

I would like to thank Dr Lesley Baillie, Director of the CNMR, Julie Hogg, Deputy Chief Nurse and research lead, and Dr Lih-Mei Liao, for offering NMAHPs this unique opportunity and to the UCLH Charity for providing generous funding for the fellowships. As the momentum behind developing a strong clinical academic NMAHP workforce grows nationally, time will demonstrate how investments such as these and a continued provision locally will improve the outcomes and experiences of patients under our care at UCLH.

Further resources for development of clinical academic NMAHPs


National Institute for Health Research. Building a research career: A guide for aspiring clinical academics (excluding doctors and dentists) and their managers. Available at: www.nihr.ac.uk/our-faculty/documents/Building-a-research-career-handbook.pdf
Is my project research, service evaluation or audit? A quick guide to Health Research Authority regulations

Rachel Taylor, Senior Research Fellow, Cancer Clinical Trials Unit; Ana Martins, Research Associate, Cancer Clinical Trials Unit; Lorna Fern, Research Coordinator, National Cancer Research Institute

Introduction

Central to research governance is safeguarding patients and participants in research. As such, clarity around whether a project is research, service evaluation or audit is essential due to differing regulations governing each activity. In April 2016, the Health Research Authority (HRA) introduced new processes to centralise permission to conduct research, similar to obtaining research ethics approval. This applies to all research where NHS premises and/or NHS patients and/or NHS staff in England are participating in the project. This is different to previous regulations where i) research involving NHS staff required no approval and ii) after gaining Research Ethics Committee (REC) approval the Research & Development (R&D) department in each hospital would need to be contacted to gain specific approval. This latter activity often required completing additional non-standard documents and resulted in significant delays in enabling a study to open. The new HRA processes are designed to make applications to conduct research simpler. However, how do you know if your project is research?

“Central to research governance is safeguarding patients and participants in research. As such, clarity around whether a project is research, service evaluation or audit is essential due to differing regulations governing each activity.”

There are a number of useful online tools and resources to help you understand the regulations around research, such as the above on the HRA’s website.

Research, service evaluation or audit?

The HRA provide a helpful leaflet to guide healthcare professionals to determine whether their project is research, service evaluation or audit (HRA 2009). The purpose of the activity is key to determining which it is:

• Research: designed and conducted to identify what we should be doing.
• Service evaluation: designed and conducted to define or judge what we are currently doing.
• Audit: designed and conducted to determine if we are doing what we should be doing.

While all three activities can be conducted in a similar way, the focus of each step in the process is different (see Table 1 overleaf).
To assist healthcare professionals in deciding on what type of project they are undertaking, and therefore what regulatory approval(s) they require, the HRA provide a decision tool.³

This asks three key questions:
• Are the participants in your study randomised to different groups?
• Does your study protocol demand changing treatment/patient care from accepted standards for any of the patients involved?
• Are your findings going to be generalisable?

If the answer to any of these questions is ‘Yes’ then the project is research and you will be prompted to the second decision tool to determine whether REC approval is required, see more at www.hra-decisiontools.org.uk/ethics

This asks more detailed questions about the study design, participants and data being collected. At the end of both decision tools, you enter your project title so you can print out the decision to keep as evidence that the project has been reviewed.

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Table 1. Summary of the differences between research, service evaluation and audit (HRA 2009)

<table>
<thead>
<tr>
<th></th>
<th>Research</th>
<th>Service evaluation</th>
<th>Audit</th>
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</thead>
<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td>Designed to generate generalisable new knowledge; testing hypotheses.</td>
<td>Designed to answer: ‘what standard does this service achieve?’</td>
<td>Designed to answer: ‘does this service reach a predetermined standard?’</td>
</tr>
<tr>
<td><strong>Focus</strong></td>
<td>Addresses clearly defined questions, aims and objectives.</td>
<td>Measures current service without reference to a standard</td>
<td>Measures against a standard</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td>Evaluating or comparing interventions, especially new ones; Exploring how interventions and relationships are experienced.</td>
<td>Intervention already in use in practice. Choice of treatment is decided according to guidance, professional standards and/or patient preference.</td>
<td></td>
</tr>
<tr>
<td><strong>Data collection methods</strong></td>
<td>Usually involves collecting data that are additional to routine care. May involve treatment, samples, investigations or procedures additional to routine care.</td>
<td>Involves analysis of existing data but may include administration of questionnaires or interviews/ focus groups.</td>
<td></td>
</tr>
<tr>
<td><strong>Sample</strong></td>
<td>May involve allocation to an intervention group; Clearly defined sampling framework with conceptual or theoretical justification.</td>
<td>No allocation to intervention; intervention chosen before service evaluation or audit.</td>
<td></td>
</tr>
<tr>
<td><strong>Randomisation</strong></td>
<td>Can involve randomisation.</td>
<td>Never.</td>
<td></td>
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</table>
Who to get approval from

The two main bodies for granting approval are the REC and HRA (Table 2) although there are other organisations granting approval depending on the type of research being undertaken, for example National Offender Management Service for research on prisoners and Confidentiality Advisory Group for research using patient information without their consent.

Details about the various review bodies are available on the HRA website. It is also worth checking if there are other bodies from whom you need to get approval.

<table>
<thead>
<tr>
<th>Table 2: Who is regulatory authority approval required from?*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of project</strong></td>
</tr>
<tr>
<td>Research involving patients, families and carers (in the NHS or private sector)</td>
</tr>
<tr>
<td>Research involving people working in the NHS only</td>
</tr>
<tr>
<td>Service evaluation</td>
</tr>
<tr>
<td>Audit</td>
</tr>
</tbody>
</table>

*Additional approval will be required for research using investigative medicinal products, medical devices, radioactive substances, human embryos, storing tissue, using patient information without consent or involving prisoners.

How to obtain approval

All research applications need to be submitted through the Integrated Research Application System (IRAS). If you have a complete protocol written before you start the application and have considered all the ethical issues, then the IRAS application is straightforward. The Joint Research Office (JRO) have a template protocol that will ensure you cover all the relevant sections. If you are not familiar with the IRAS then support is available through their website and at the JRO and Centre for Nurse and Midwife Led Research (CNMR) within the Trust.

“All research applications need to be submitted through the Integrated Research Application System (IRAS) – support for this process is available on the IRAS website and at the JRO and CNMR within the Trust.”

What happens if I do research without approval?

If you conduct research without appropriate approvals, this can have an impact on patients as you could be exposing them to risks that would have been identified if approval had been sought. There will also be an impact on the evidence-base because results will not be publishable and, finally, if you are a member of a professional organisation, then you may have breached your code of conduct so there will be the resultant consequence of this.

Conclusion

Central to research governance is safeguarding patients and participants in research. Rather than viewing regulatory authorities as burdensome, they need to be viewed as a facilitating body to advocate for participants, but also to guide and support researchers.

References

3. www.hra-decisiontools.org.uk/research
5. www.myresearchproject.org.uk

Further references


The development and evaluation of the UCLH Cancer CNS Community of Practice

Kay Eaton, Consultant Nurse for Cancer; Alison Hill, Trust Lead Cancer Nurse

Introduction
The UCLH cancer Community of Practice (CoP) was established in 2015, following the recommendations of an in-depth review undertaken by the Consultant Nurse for Cancer.

Evidence from The National Cancer Patient Experience Survey (NCPES 2010) and subsequent national surveys highlighted that, across the UK, the role of the cancer CNS plays a vital role in supporting patients but that patients wanted easier access and faster response times when contacting the CNS. Both qualitative and quantitative research methods were used in exploring the breadth of 55 individual cancer CNS roles, and in identifying the gaps in cancer CNS service provision at UCLH.

The challenges CNSs faced in their roles identified from the data analysis are detailed below. The findings and recommendations detailed in the report were the catalyst and rationale for the development of the UCLH Cancer CNS Community of Practice which provided evidence that the role and support for the CNSs needed to adapt and change to reflect current needs of the Trust’s services.

Key challenges identified for the Cancer CNS
- Increasing caseload and complexity of workload.
- Inability to provide one-to-one support to all patients.
- Lack of capacity to undertake all components of the CNS role.
- Administrative overload and lack of administrative support.
- Lack of availability of clinic rooms for CNS use to see patients in privacy.
- No absence cover for stand-alone CNS roles.
- Variable education preparation for the transition to CNS role.
- Lack of understanding of the role in the Trust as a whole.

What is a Community of Practice?
Definition of a Community of Practice: ‘A group who can share a concern or passion for something they do and learn to do it better by regular interaction.’

A Community of Practice is a group of people who do similar work and meet at regular intervals, usually for at least a day, to share ideas, learn together and identify opportunities to collaborate in order to do things quicker, better or more cost effectively. The relationships built during the Community of Practice events create a foundation of goodwill and trust that encourages collaboration and mutual support between the meetings (Eaton, K., Hill, A., & Lank, E. 2014).
Aims of the UCLH Cancer Community of Practice

- To build stronger relationships, facilitate collaboration, support, and experience sharing.
- To learn/reflect on common themes of the roles as well as differences.
- To identify areas of policy and/or practice that the CNSs would like to influence.
- To develop a stronger collective voice.
- Effectively communicate the value of the CNS role.
- Personal and career development.

The UCLH Cancer CNS Community of Practice model

Macmillan Cancer Support funded the venue costs and cost of an external facilitator. Senior nursing leadership was provided by the Trust Lead Cancer Nurse and the Consultant Nurse for Cancer who were the co-leads of the community.

The Community of Practice was launched by an initial two-day residential event attended by the Chairman. Senior sponsorship (Chief Nurse) was important to give organisational support to the initiative. External facilitation led to a ‘safe space’ and an ability to create an agenda not focussed on operational issues but on professional development. The co-leadership of the group was vital to promote a ‘can do’ attitude and role model collaborative working. A CNS Steering Group ensured that the agenda remained focussed on the needs and wishes of the group.

Each event provides certificates of attendance ensuring that the wider Trust community understands the purpose of the meetings.

Work-streams developed by the Community of Practice

At the initial residential meeting, some key areas of focus emerged for the Community and these remain integral to the work plan:
- Interface with chemotherapy pathways.
- Work more effectively with primary care.
- Leadership of CNS roles.
- Income generation.
- Training and skills acquisition.
- Facilitation skills.

Wider implications and impact of the Community of Practice

There have been a number of areas of impact for the Community, both in UCLH and in cancer nursing more generally, and these are likely to increase with time and confidence of community members.

UCLH has now developed a Community of Practice for all CNSs in the Trust which has built on the work of the cancer CoP and has confirmed the value of this type of approach. The value can also be quantified in the increased confidence of the cancer CNS and in particular their contribution to Trust-wide and external meetings. This has been enhanced by offering the CNS’s experience and training in chairing the group meetings, presenting and facilitating sessions.

The Community has also enabled indirectly the increased number of Lead Cancer CNS posts, which now number 10, and there are only two tumour groups which still do not have such roles. This combined with the increased numbers of Macmillan Cancer Support Workers has changed how the cancer CNS teams operate through a new skill mix and approach to managing workload.

The Community is also involved in a piece of collaborative research funded by the Burdett Coutts Fund. This has led to more CNSs undertaking and being involved in a clinical research project.

Following UCLH’s example of developing a successful CoP, there are now similar Communities of Practice in Southampton and two acute hospital NHS Trusts in London. The development and evaluation of the work has been published and was shared as a poster at the CNMR Conference in February 2017.

References


Why Not Workshop – Statistics
Mr Rob Shortman, 8th September, 1.00pm–3.00pm

This workshop aims to provide participants with an overview of the key statistical concepts used within clinical research.

For further details and to register, please contact the CNMR rsc.cnmr@ucl.ac.uk