

Five things you need to know:

A Pilot Training Programme for Health and Social Care Professionals providing Palliative and Oncological Care to Lesbian, Gay and Bisexual Patients

Funded by
Irish Hospice Foundation
Irish Cancer Society
Health Service Executive

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Foreword

A diagnosis of cancer, or of a life limiting illness requiring palliative care is usually a dramatic and life changing event. Not only is the patient affected, but also their family and friends. This is often a stressful time, for patients and their social and family network. This is recognised by Oncology and Palliative Care teams, who usually provide support and counselling to the patient and family and friends. Respect is very important and lesbian, gay, bisexual and transgender people are equally deserving of respect as the rest of the population, whether they are affected by a new diagnosis as a patient, a partner, a family member or a friend.

Many Oncology and Palliative Care practitioners have good communication skills, and a good understanding of the effect of serious illness on a patient and their social network. The importance of maintaining and developing skills to provide appropriate affirmative care for LGBT people, as patients, or as part of the social network of patients is clear. This pilot project demonstrates how education and training to support staff to allow them improve care for patients and their families can be provided.

I hope that this education and training, and its evaluation will continue.

Dr. Regina McQuillan, FRCPI
Palliative Medicine Consultant

Preface

Relationships matter. And in the face of a life threatening illness relationships matter more. The diagnosis of a life threatening illness quite naturally unearths some of our most intimate fears and personal vulnerabilities. Modern healthcare recognizes the need to care for the individual in the context of these psychological and relational realities.

There have been significant changes in the conditions of life for lesbian, gay and bisexual (LGB) people in Ireland in the last 20 years, including the decriminalisation of male homosexual acts in 1993, the introduction of comprehensive equality legislation, and most recently the passing of the Civil Partnership Act (2010). However, the national and international research indicates that when it comes to accessing and receiving healthcare LGB people continue to face significant challenges. Challenges which include living with minority stress due to ongoing discrimination and lack of inclusiveness.

In response to this, a growing number of professional bodies have developed best practice guidelines. The Irish College of General Practitioners (ICGP) and the Irish Institute of Mental Health Nursing (IIMHN), in conjunction with the Gay and Lesbian Equality Network (GLEN), have developed an evidence based, five step model of best practice for their members that enables them to provide optimal care to LGB patients.

The relevance of this issue for oncology and palliative care patients is something that I have been aware of for many years in the course of my clinical work. I have on numerous occasions watched some of the most caring and competent healthcare professionals provide care to LGB patients and sometimes struggle, often skirting the issues associated with sexuality out of a genuine attempt to not offend. The desire to provide compassionate and competent care often compromised by the fear of saying the wrong thing.

The current project came about in an effort to bridge this gap; to translate the five step model of best practice into a training programme which could be delivered directly to frontline staff working with LGB patients. **The training programme operationalises the guidelines for use within the clinical setting. It is the first of its kind in considering the needs of palliative and oncology patients and may be seen as a model of best practice in the area both nationally and internationally.**

This project came to life because of the generous support from our primary funders: the Irish Hospice Foundation (IHF) and the Irish Cancer Society (ICS). The project owes much to the energy, insight and dedication of the project worker, Dr Finn Reygan. Finn worked on behalf of the Project Steering Group and delivered a very robust, deeply human and engaging training programme and evaluation.

The results of the evaluation of this project provide a very clear mandate for the training to be made available to all staff involved in patient care. We look forward to advancing and mainstreaming this training programme and in so doing to further equip our colleagues to continue delivering the compassionate and competent care modern healthcare requires.

Paul D'Alton

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Ms. Barbara Sweeney, St Francis Hospice
Ms. Pauline Ui Dhuibhir, Our Lady's Hospice and Care Service

Finally, the authors would like to thank all staff who gave of their time to attend the trainings. It was heartening to see the interest and enthusiasm with which health and social care staff came to this training.

About the authors

Dr. Finn CG Reygan is a psychologist who specialises in the area of gender and sexualities. He was a Visiting Scholar at the University of California, Berkeley for a number of years, holds a PhD in lesbian, gay, bisexual, transgender and queer (LGBTQ) Psychology from University College Dublin and a postdoctoral fellowship at the University of KwaZulu Natal, South Africa. He also holds an MSc in Equality Studies and has worked at Gay Men's Health Crisis (GMHC) in New York City. He has a record of publications and conference presentations in areas of concern to LGBTQ populations including: HIV/AIDS; LGBT youth; sexuality and spirituality; and LGBT oncology and palliative care.

Dr. Paul D'Alton is Head and Clinical Lead of the Department of Psycho-oncology at St Vincent's University Hospital, Dublin 4. The Psycho-oncology team is multidisciplinary and provides psychological services to cancer patients throughout the hospital at all stages of their illness. Paul completed his clinical psychology training in Trinity College, Dublin. Paul's primary area of clinical interest is the application of mindfulness-based interventions in health care. He completed his internship and teacher training at the University of Massachusetts (USA) where mindfulness-based interventions in healthcare originated. He teaches on several post-graduate programmes at University College Dublin, the Royal College of Surgeons in Ireland and Trinity College Dublin. Paul is principal investigator on the ongoing multidisciplinary *Living with Dying* study that is examining the psychological landscape of death in the acute hospital. He is also co-principal investigator on *Mindfulness under the Microscope* study – a psychoneuroimmunological examination of mindfulness in healthcare. He has completed a number of funded research projects – the most recent was a training programme for oncology and palliative care staff which was presented at the American Psychological Association Convention in Washington DC in 2011. Paul is current chair of the PSI Equality and Diversity Working Group (EquIP) and the Loss, Dying and Bereavement Special Interest Group. In 2009, Paul was appointed as an expert member of the St Vincent's University Hospital Medical Research and Ethics Committee. He is on the Board of Directors of the Irish Association of Palliative Care and on the Council of The Psychological Society of Ireland.

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Terminology

Terminology in the field of gender and sexual minorities is constantly evolving. Two of the commonly used acronyms are LGB (lesbian, gay and bisexual) and LGBT (lesbian, gay, bisexual and transgender). The following is a list of terms used throughout this report:

<i>Lesbian</i>	A lesbian woman is romantically, emotionally and/or sexually attracted to other women
<i>Gay</i>	A gay man is romantically, emotionally and/or sexually to attracted to other men. Many lesbian women also identify as gay
<i>Bisexual</i>	A bisexual person is romantically, emotionally and/or sexually attracted to people of both sexes
<i>MSM</i>	MSM (men-who-have-sex-with-men) is a term used to refer to men who sex with other men but do not necessarily identify as gay or bisexual
<i>Transgender</i>	Transgender is an inclusive umbrella term that describes a wide range of gender identity and expression
<i>Gender minority</i>	Gender minorities include those people whose gender identity does not conform to societal norms
<i>Sexual minority</i>	Sexual minorities include those people whose sexual orientation, sexual identities or sexual practices do not conform to societal norms
<i>Affirmative care</i>	Affirmative care requires familiarity with the specific health issues of minority group patients as well as the provision of sensitive, appropriate and accessible health services to these groups
<i>Minority Stress</i>	Chronically high levels of stress experienced by members of stigmatized minority groups

Other terminology relevant to this report and the project it outlines include:

<i>Oncology care</i>	Oncology care refers to the care provided to people living with cancer.
<i>Palliative care</i>	Palliative care refers to the care provided to those people with non-curative illnesses, including end-of-life care

Executive summary

There have been significant changes in the conditions of life for lesbian, gay and bisexual (LGB) people in Ireland in the last 20 years, including the decriminalisation of male homosexual acts in 1993, the introduction of comprehensive equality legislation and the passing of the Civil Partnership Act (2010). Nevertheless, the national and international research indicates that LGB people continue to face challenges when attempting to access and receive healthcare. These challenges include homophobia and the negative dividend of living with minority stress due to ongoing discrimination.

Given these challenges, a growing number of professional bodies have developed best practice guidelines. The Irish College of General Practitioners (ICGP) and the Irish Institute of Mental Health Nursing (IIMHN), in conjunction with the Gay and Lesbian Equality Network (GLEN), have developed an evidence based, five step model of best practice for their members that enables them to provide optimal care to LGB patients. On the basis of these professional guidelines and as a result of the changing mores of Irish society, the Irish Hospice Foundation (IHF), the Irish Cancer Society (ICS) and the Health Service Executive (HSE) funded a pilot project to train health and social care professionals on providing care to LGB patients.

The project was a groundbreaking initiative and the first of its kind in Ireland. While a programme exists in New York City to train oncology care providers working with lesbian, gay, bisexual and transgender (LGBT) populations, few educational initiatives exist internationally on providing palliative and oncology care to sexual minority populations. Therefore, the current project broke new ground and may be seen as a model of best practice in the area both nationally and internationally. The project aimed to rectify a service gap and to function as the pilot study for a larger, long-term project that will provide training for nursing, medical and health and social care staff working with LGB patients in acute hospital, hospice and community palliative care teams across Ireland.

Project aims

The aim of the project was to support palliative and oncology care staff to deliver affirmative care to their LGB patients and families. It also aimed to increase palliative and oncology care staff awareness of LGB issues relevant to help-seeking behaviours in hospital and hospice settings and to provide staff with access to training materials that are easily accessible and transferable to other palliative care and oncology services.

Project outline

The project developed a brief, 50 minute training module for professionals providing oncology and palliative care to LGB patients. The project ran for eight months, began in November 2010 and finished in June 2011. Over 200 health and social care professionals participated in 17 trainings across the four sites included in the project. These Dublin sites were:

- St. Vincent's University Hospital, Elm Park, Dublin 4
- Beaumont Hospital, Beaumont Road, Dublin 9
- Our Lady's Hospice and Care Services, Harold's Cross, Dublin 6W
- St. Francis Hospice, Station Road, Raheny, Dublin 5

Evaluation and findings

The evaluation of the project occurred in two ways: participants completed questionnaires at the end of each training and one participant from each of the four sites also participated in an interview with external evaluators. Feedback from participants was overwhelmingly positive. The vast majority of participants found the training to be of high quality, would recommend it to their colleagues, were interested in further training in the area and found the training useful for their practice. Participants also became more familiar with LGB-related language and terminology, became more knowledgeable of LGB health issues and reported becoming more confident in providing care to LGB patients. Participants requested further training in the area, greater availability of the training across the health services in Ireland, and inclusion of the training in postgraduate courses for trainee health and social care professionals. The training also had a number of limitations. It was brief, at only 50 minutes in length, and therefore did not provide the opportunity for participants to explore in-depth some of the issues presented in the training. It was also not possible within the parameters of the project to measure if and how the information provided during the training would be translated into practice by participants.

Introduction

This report outlines step-by-step the various stages in the development of the project. It provides an outline of the project, research in the area, the stages in the development of the project, the evaluation of the project and findings, the trainer's experience, conclusions and recommendations. The appendices also include all material used during the course of the project including evaluation forms, handouts and the slides used during training workshops.

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Literature review

In 1993 male homosexual acts were decriminalised in Ireland and since then there has been much progress in progressing the rights of LGBT people. This progress includes the Equal Status Acts (2000, 2004) that prohibit discrimination on nine grounds, including sexual orientation, and the Civil Partnership Act (2010) that gives legal recognition to same-sex relationships. Also in 2010 the Attorney General's office dropped its challenge to Dr. Lydia Foy, a transsexual woman, who petitioned to have her birth certificate amended. In short, the 1990s and 2000s saw profound changes in the conditions of life for many LGBT people.

Nevertheless the research indicates that homophobia and minority stress continue to negatively impact on the health and well-being of LGBT people in Ireland. In particular, the research points to the challenges that LGBT people face when accessing and receiving healthcare (Gibbons, Manandhar, Gleeson & Mullan, 2007).

A number of reports point to the health challenges that LGB people face and to the difficulties that they encounter when accessing health services. The *Supporting LGBT (Lesbian, Gay, Bisexual and Transgender) Lives* (Mayock, Bryan, Carr & Kitching, 2009) study of 1,110 LGBT people in Ireland found that healthcare providers knew about respondents' LGBT identities in only 44% of cases, that only 40% of respondents felt respected as an LGBT person by their healthcare provider, and that respondents were often reluctant to disclose both their sexual orientation and related health concerns to their healthcare provider for fear of a negative response. Other research has highlighted the stigma and minority stress experienced by young people who are LGB (Kelleher, 2009).

Reports in Ireland also address the LGB-related issues that health care providers—particularly mental health nurses and GPs—face when working with LGB patients. In *Lesbian, gay and bisexual patients: The issues for general practice* (Allen, 2008) the ICGP indicate that anti-gay bias may result in LGB patients receiving sub-optimal care. The ICGP argues that inclusive practice requires both familiarity with the specific health issues of LGB patients as well as the provision of accessible and appropriate health services to LGB people. The ICGP recommend that GPs be provided with resources to improve their service provision to LGB patients and suggest five steps in this regard. They recommend that GPs: stay informed on LGB health concerns, not assume that all patients are heterosexual, respond positively when patients disclose their sexual orientation, become aware of and challenge anti-gay bias, and that they clearly demonstrate that their general practice is LGB-inclusive.

In *Gay, lesbian and bisexual people: A good practice guide for mental health nurses* (Higgins & Allen, 2010) the Irish Institute of Mental Health Nursing (IIMHN) recommends that mental health nurses become aware of the specific health needs and issues of concern to LGB people. They point out that, in line with An Bord Altranais' Code of Professional Conduct for nurses and midwives, professional anti-gay bias falls below the required standard of professional practice of the IIMHN. The IIMHN indicates that a good understanding of LGB-related issues is central to providing inclusive mental health services. These LGB-related issues include: minority stress, resilience, depression, self-harm, suicidal behavior, grief, LGB parenting, and general health-related behaviours. The IIMHN recommend that mental health nurses: be aware of LGB mental health issues and gay-specific stressors, avoid presuming that all service users are heterosexual, respond supportively when service users disclose they are LGB, challenge anti-gay bias by adopting a gay-affirmative approach, and demonstrate that the mental health practice is inclusive of LGB people. These recommendations – and those of the ICGP outlined previously—for mental health nurses and GPs working with LGB patients are also relevant to nursing and medical staff more generally as well as health and social care professionals such as psychologists and social workers. In particular, these recommendations extend to nurses and medical staff providing oncology and palliative care services to LGB patients in Ireland, for whom best practice guidelines and training programmes have yet to be developed. The Irish Hospice Foundation (2010) Hospice Friendly Hospitals *Quality Standards for End-of-Life Care in Hospitals* report (p. 95) defines the principles of palliative care as including:

- Communication which is open and sensitive
- A whole person approach which takes into consideration a person's circumstances, spirituality and sexuality

- Quality of life including the best possible symptom control
- Care for all concerned (family and those important to the patient)
- Respect for patient autonomy and choice

In this regard a palliative care approach is therefore one that is holistic and takes into consideration a person's sexuality.

Little research has been undertaken specifically in the area of oncology and palliative care with LGB patients. Nevertheless, Glackin and Higgins' (2008) study of same-sex bereavement in the Irish context indicates mixed experiences of palliative and end-of-life care for LGB people. For example, one participant said (p. 301):

I remember people saying to me, 'You've lost a good friend', and I felt something almost clicking in my head and thinking, I almost exploded, because I thought, 'I haven't lost a friend, I've lost someone that's been part of my life for 25 years, since I was 18. And 25 years down the road, I've lost this person'. And I mean together for 25 years, so it's a huge amount...everyone has their ups and downs, but 25 years down the road, we were still together. And I thought—'a friend, I haven't lost a friend. Yes, I've lost a friend, but I have lost SO much more, and I actually remember thinking, 'You've no idea'.

In the UK Almack (2010) has found that LGB patients face particular issues in palliative and end-of-life care such as homophobia and lack of recognition of same-sex relationships. In the USA, an Institute of Medicine (2011) report highlighted the paucity of LGBT end-of-life and palliative care research.

In terms of oncology care, O'Hanlan (2006) points out that the Women's Health Initiative and the Nurses Health Study II found lesbian women to have more risk factors for a number of cancers. These risk factors include nulliparity, tobacco and alcohol use, and obesity (see Valanis et al., 2000; Case et al., 2004; Cochran et al., 2001). Valanis et al. (2000) indicate that lesbian women may attend for fewer mammograms and have higher rates of breast cancer and that reduced parity and less use of contraceptives, along with risk of overweight and endometriosis, may lead to an increase in ovarian and uterine carcinomas among lesbian women. O'Hanlan (2006) points out that many lesbians report previous sex with men thereby indicating the need for Pap tests though lesbian women may not believe they need them. Dibble, Roberts and Nussey (2004) found that lesbian women had a significantly higher 5-year and lifetime risk for developing breast cancer compared with heterosexual women due to reduced use of birth control pills, higher rates of nulliparity and higher numbers of breast biopsies. In terms of men who have sex with men (MSM), Goldstone et al. (2011) suggest that HIV-positive MSM are at higher risk of anal HPV infection which places them at higher risk of anal cancer than the general population. Goldstone et al. (2011) found a high prevalence of human papillomavirus (HPV) among a sample of sexually active, young MSM and that the anal canal was most often the site of infection. Vajdic et al. (2009) also found that HPV infection was almost universal in a sample of homosexual men, that there was a wide variety of HPV genotypes and that co-infection was common. Furthermore Vajdic et al. (2009) found anal HPV infection to be more prevalent and diverse in HIV-positive as opposed to HIV-negative homosexual men. Vajdic et al. (2009) argue that homosexual men are at increased risk of HPV-related anogenital disease and that this includes anal cancer. Chin-Hong et al. (2005) found sexually active HIV-negative MSM to have a high prevalence of anal squamous intraepithelial lesions (ASILs) which they suggest may result from continuing exposure to HPV.

Overall the research, both in Ireland and internationally, indicates that homophobia and minority stress impact on the health and well-being of LGBT people. As a result of the perceived hostility of healthcare providers a large minority of LGBT patients in Ireland withhold information about their identities from their healthcare providers (Mayock et al., 2009). Homophobia and the invisibilising of LGBT identities also occurs in end-of-life and palliative care both in Ireland and internationally. However LGBT populations have discrete healthcare needs that providers are often unaware of such as: increased alcohol and substance use, increased levels of anxiety and depression (Mayock et al., 2009) and increased risk for a number of cancers including breast cancer and anal cancer, though more research is needed in this area. These risk factors, combined with lower rates of screening for a range of health conditions, may lead to a higher incidence of a number of illnesses among LGB patients.

Project development

The development of the project went through a number of stages and the following outline is intended to chart this development, to highlight significant issues that arose in the course of the project and to function as a resource for future trainers. In this regard Kotter (2007) presents an eight step model of change that is useful in charting the development of the project:

Step 1 Create urgency

Kotter (2007) argues that for change to happen there needs to be a sense of urgency around the need for this change. In Ireland the Irish Hospice Foundation (IHF) and the Gay and Lesbian Equality Network (GLEN) identified the need for greater awareness of the disparities faced by LGB patients in the healthcare system. Dr. Paul D'Alton and GLEN identified a particular gap in oncology and palliative care and began informal discussions with people in the field.

Step 2 Form a powerful coalition

Convincing people of the need for change requires strong leadership and support from stakeholders. In this sense it is not enough to simply manage change because leadership is also necessary. Dr. D'Alton and Odhran Allen, Director of Mental Health Policy at GLEN, brought together a team of influential people to create a 'change coalition'. These people from the hospitals, hospices, academia and the professional bodies formed a steering group to oversee the project. Steering group members brought with them a wide range of expertise in research, teaching, clinical work, healthcare management, social change and LGBT issues. Stemming from consultation with this group and discussion with representatives from Transgender groups, it was decided to limit the pilot training programme to members of the LGB community. This decision was taken given the medical complexity often associated with transgendered individuals.

Step 3 Create a vision for change

The start of a plan for change often involves many great ideas that need to be linked coherently so as to form an overall vision. The steering group discussed at length different ways to respond to unequal service provision to LGB patients. The idea of a half-day training was initially mooted but was discarded because of the economic climate and attendant cutbacks in Ireland. The group narrowed feasibility to a brief training that would be delivered on site to health and social care staff in four pilot sites in the Dublin area.

Step 4 Communicate the vision

Representatives from the various pilot sites returned to their respective organisations and began communicating the vision of the project to other staff responsible for education and training. They also began communicating this vision to the potential funders.

Step 5 Remove obstacles

Given the economic climate and the novelty of the topic, steering group members believed that flexibility was a key aspect in negotiating the challenges that arose in the course of the project and the process was understood as one of 'eat and learn'. Central to the development of the project was the creation of a powerful and recognised steering group with respected expertise in field as well as the recruitment of a

project worker with relevant expertise. The project worker, Dr. Reygan, held a PhD in LGBTQ Psychology and was considered an optimal fit for the position.

Step 6 Create short-term wins

Short-term goals for the project included the importance of inserting the training into existing educational infrastructures in the sites included in the project. Steering group members also considered it important to provide a 'win situation' for educators and the evaluation of the programme helped to provide further energy and impetus. Given the brevity of the training and the development of relationships across institutions and disciplines, the structure of the training also allowed for large numbers of participants to attend.

Steps 7/8 Building on and anchoring the change

Given the change introduced by the project, the job of the steering group going forward is to build on and anchor this change. This task includes building on the findings from the evaluation and on the recommendations included in the report. In particular, the steering group is tasked with embedding the model into existing education frameworks in hospitals, hospices and other healthcare settings. Also, given the interest generated by the training in the universities and pilot sites, it is the steering group's responsibility to deepen these relationships, to continue to raise awareness around the issues and to support the introduction of the training onto undergraduate and postgraduate courses for trainee health and social care professionals.

Project timeline

The project was overseen by the expert steering committee and directly coordinated and supervised by Dr. Paul D'Alton, Head of the Department of Psycho-oncology, St Vincent's University Hospital. Dr. Reygan began developing the training materials by completing an international literature review and by using the findings and existing materials available in the Irish context from the ICGP, IIMHN and GLEN. In applying for ethical approval for the training workshops, the ethics committees in Beaumont Hospital and St. Vincent's University Hospital deemed ethical approval unnecessary because they considered the project to be a staff training. The ethics committees of Our Lady's Hospice and St. Francis Hospice granted ethical approval for the training and its evaluation and so workshops began in February 2011 and continued through May 2011. In January 2011 contact had been made with members of staff who acted as facilitators in publicising the trainings and in recruiting participants in the four pilot sites. In the ongoing development of the project, the lessons learned from the delivery of each session were used to refine and improve the training materials and delivery format. Participants were also given a handout (see Appendix C) at the completion of each training which included related reading and links for further information.

The final report was written up, made available to stakeholders and published on Lenus, the Irish Health Research Repository. The training materials were also made available in multiple formats, including a module delivered online by means of the HSE's online training forum, HSEland (www.hseland.ie). This was done so as to allow staff members to access the training in their own time or from the units in which they worked. A version of the final report was submitted for publication in the journal of *Psycho-oncology* and articles on the project were published in the *Irish Medical Independent* and in the Irish Association of Palliative Care (IAPC) newsletter. Information on the training was also presented at the Irish Association of

Palliative Care (IAPC) Annual Seminar (2011) in Dublin, at the American Psychological Association (APA) Annual Convention (2011) in Washington D.C. and at the International Psycho-oncology Society (IPOS) Annual Conference (2011) in Turkey.

Training structure

The project developed a training programme for health and social care staff providing oncology and palliative care to LGB patients. The training module (Appendix D) included information on language use, some research in the Irish context and the five steps to best practice as recommended by the ICGP, IIMHN and GLEN (see Figure 1).

5 steps to best practice with LGB patients

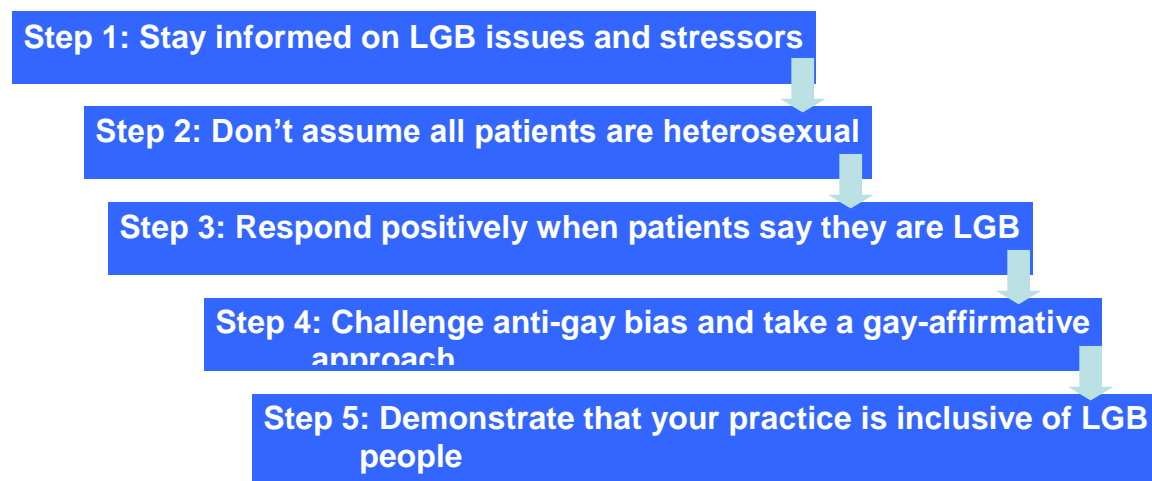


Figure 1 5 Steps to best practice with LGB patients

This core training was approximately 30 minutes in length. Beyond this core training there was an additional component that focused specifically on oncology and palliative care. The training was structured in such a way as to allow for its applicability to other specialty areas beyond oncology and palliative care. In this sense discipline-specific information could be replaced with information on other specialty areas such as coronary care and tailored to specific disciplines as required. The training was intended to fit the requirements and needs of diverse health and social care practitioners and to provide a platform from which to provide more specialised training in the area of LGB health and well-being.

Evaluation

The project was evaluated in two ways. Firstly, participants completed an evaluation questionnaire at the end of the training (see Appendix B). Secondly, one participant from each of the four sites participated in an interview of approximately 20 minutes with an external evaluator (see Appendix B). The results from these two phases of the evaluation process are presented below. Just over 200 (N=201) participants attended 17 individual trainings across the four sites. Participants' age ranged from 18 to over 60 with just over half of participants aged between 30 and 49. The majority of participants (77.6%) were female and participants came from a wide range of health and social care backgrounds and were: nurses (44.3%); health care assistants (11.9%); social workers (7.5%); occupational therapists (5.5%); doctors (5%); chaplains (2.5%); and physiotherapists (2.5%).

Results

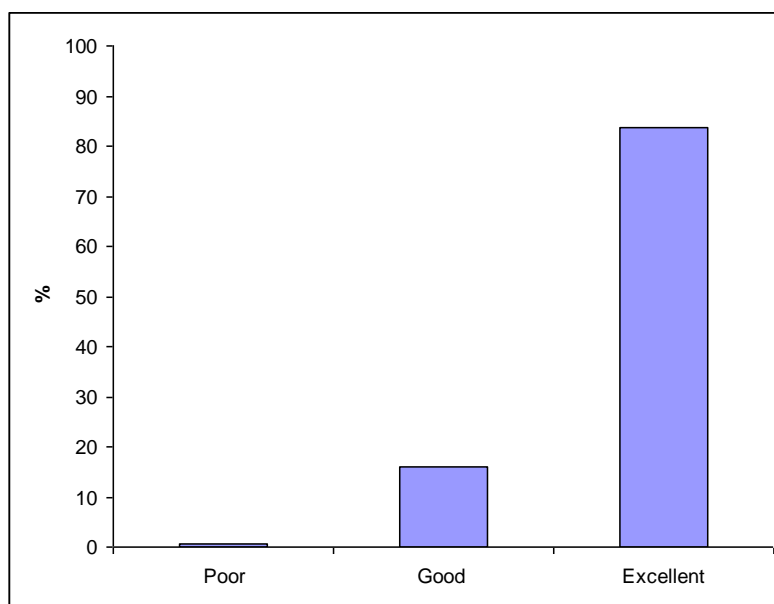


Figure 2 Quality of Training

Figure 2 (above) shows that the majority of participants found the quality of the training, including delivery and materials, to be excellent (83.6%) or good (15.9%).

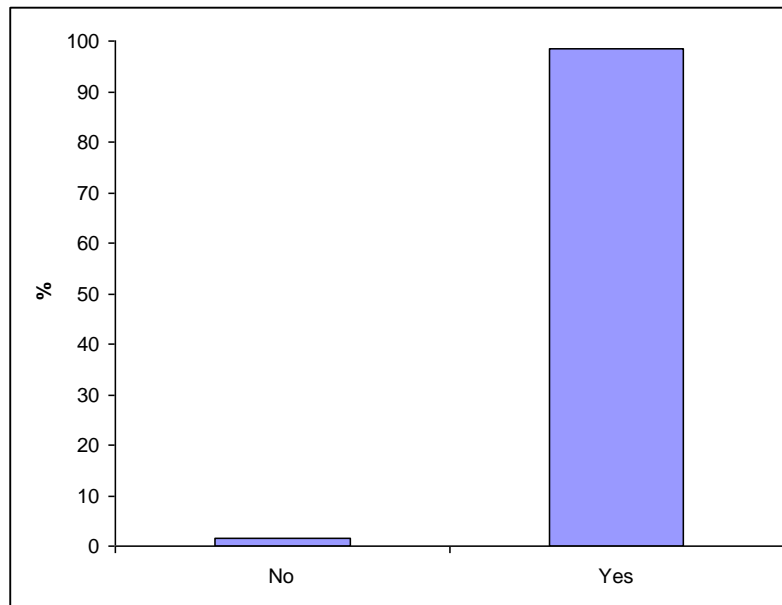


Figure 3 Participants recommending training

Figure 3 (above) indicates that the majority of participants (98.5%) would recommend the training to their colleagues and friends.

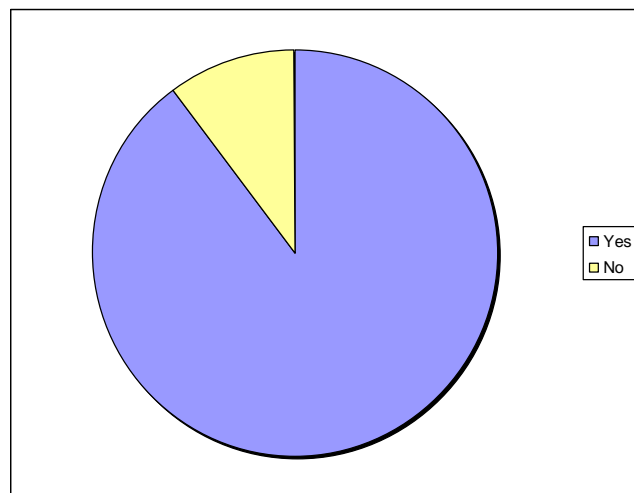


Figure 4 Interest in further training

Figure 4 (above) indicates that the majority of participants (89.6%) were interested in further training in the area. The vast majority of participants (98.5%) also reported that the training was useful for their practice and the majority (93.5%) reported that the training had increased their awareness of LGB-related issues.

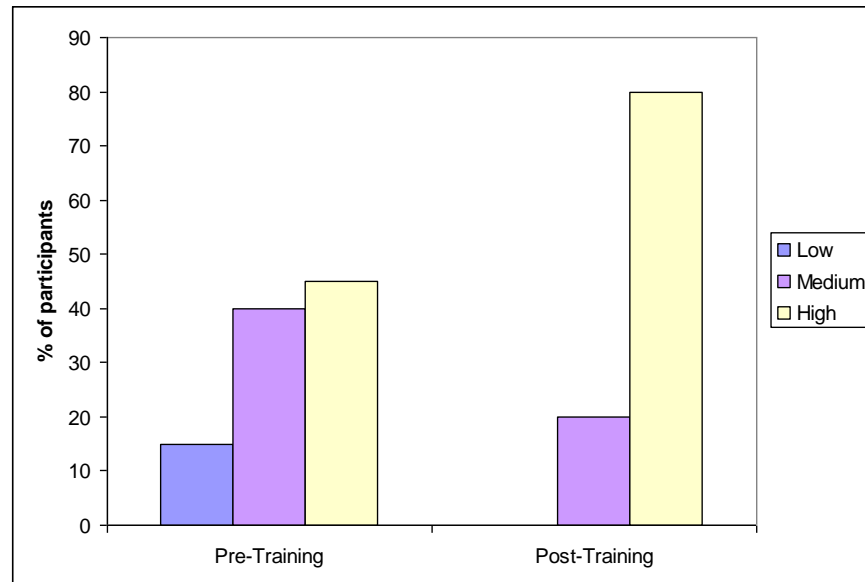


Figure 5 Comfort with LGB terminology pre- and post-training

Figure 5 (above) indicates that over 40% of participants had a high level of comfort with LGB terminology before the training and that this figure increased to 80% by the end of the training. While approximately 15% of participants experienced low levels of comfort with LGB-related language before the training, almost no participants reported discomfort with LGB terminology at the end of the training. Overall participants became more comfortable with LGB-related language including terms such as: *lesbian*, *gay*, *bisexual*, *LGB* and *homophobia*.

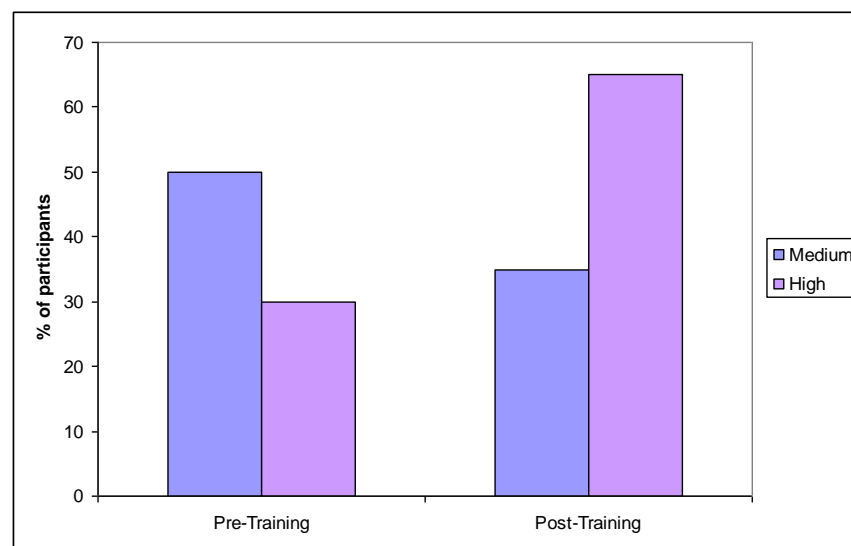


Figure 6 Confidence providing LGB care pre- and post-training

Figure 6 (above) shows that participants experienced a shift in the course of the training in terms of their confidence in providing care to LGB patients. Approximately one fifth of participants reported high levels

of confidence in providing care to LGB patients before the training and this figure rose to approximately 60% after the training.

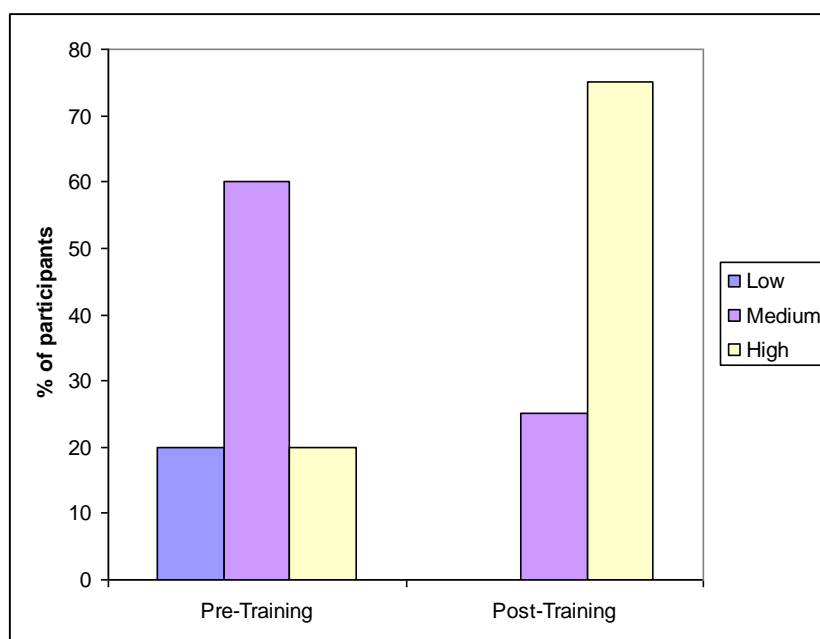


Figure 7 Knowledge of LGB issues pre- and post-training

Figure 7 (above) indicates that approximately one fifth of participants felt they had a high level of knowledge of the LGB healthcare-related issues before the training. This figure rose to approximately 75% after the training. Correspondingly, while over one fifth of participants reported low levels of knowledge of LGB issues before the training almost no participants reported little knowledge of LGB health issues after that training.

Overall the number of participants in the different disciplines and sites was not sufficient to do a between groups analysis. Nevertheless the majority (77.6%) of participants on the training were female and all participants who participated in evaluation interviews were female: that women constituted the majority of participants presumably affected both the trainings and the evaluation interviews. A thematic analysis of participants' answers to the open ended questions on the evaluation questionnaire also produced a number of recurring themes including: the high quality of the training; the need for more training in the area; the need for greater equality in the provision of healthcare in Ireland; and the need for more knowledge among healthcare providers on the needs of LGB populations.

Evaluation interviews

The following are the reports from evaluators who completed interviews with one participant from each of the pilot sites. One of these evaluation interviews took place in person and the other three were conducted over the phone.

Evaluation Interview 1

Female, 20s, Hospital

What was your personal experience of the training?

Very good, maybe too much information for one session, it is such a broad topic. Some of the other participants on my training were from overseas and maybe they didn't get it; maybe they are not used to talking about such intimate things. There was some giggling...(evaluator probe re 'your experience')...One of the best things I took from it was that it highlighted how to interact with people, to broach it on admission, not to assume someone is heterosexual. Ask open-ended questions such as "do you have a partner"?

What effect, if any, has the training had on you professionally?

Well I haven't come across any gay patients since the training. I always am open and talk to patients about their sex life and their libido—"if you need to discuss something I am here". I think I equally welcome straight partners and treat them with respect. I found the statistics very interesting, like around self-harm. We all think it would be great to have a gay best friend but you realise the difficulties they face.

What effect, if any, has the training had on care provision to LGB patients in your service?

It made me think more and maybe I need to broach things a little differently. I remember a gay couple who had been together for 25 years, they were a great experience, but not all gay people have that. It could be someone doesn't have a partner and they are not out. It helped that Finn gave us concrete facts and it was realistic how about how gay people might feel. I treat every patient as different, not just if they are LGB, so it wouldn't affect my care really.

What effect, if any, has the training had on the organisation where you work?

It's great to have more information, like GLEN's website. We have put the information up on the ward now; we have a pouch with information in it.

Is there anything else you would like to say about the training?

Just remember to be open and affirmative, don't assume anything.

Evaluation Interview 2

Female, 50s, Hospital

What was your personal experience of the training?

It was very good and informative. The group I attended with was a very open group, so the dynamic was open and very agreeable, they were also very eager to learn and discuss things. Finn could have been there all night, as they were so talkative; so he had a cohort of staff that was very in tune. If it was a group that wasn't as open as us it might have been different.

What effect, if any, has the training had on you professionally?

It was great to see the issues being discussed. I am (names a position that is involved in education) and it made me more aware of the importance of including LGB issues in education. We do include issues on sexuality but I am more aware of need to talk about LGB issues or invite someone like Finn in to talk.

What effect, if any, has the training had on care provision to LGB patients in your service?

It is difficult to say as I haven't been on the ward much since the training, but I think it would create openness, a greater openness to discussing LGB issues. Things are changing so fast and the training brought me up to date on legal changes and things like civil partnership, and that should impact on care.

What effect, if any, has the training had on the organisation where you work?

Again not sure how much it will impact on the organisation as a whole, the group that attended was specifically from oncology and people don't just die in oncology and LGB people are within all the service, so for it to have an impact it needs to be rolled out throughout the hospital. As I said we were a tuned in group and I don't think all the organisation would be as tuned in so need to think about the training for the wider context, the staff throughout the hospital.

Is there anything else you would like to say about the training?

It was very good, and it was good to see it happening, as people need to be sensitive to LGB issues and be able to respond appropriately. It was very interactive and Finn gave us the right amount of information given the time available but to be really effective it needs to be rolled out. I will be considering bringing in someone like Finn to talk to all groups who are doing courses. Overall it was worthwhile.

Evaluator comments

Participant was very positive about training. From the conversation over the phone I got a sense that this was a person who had read and considered the area of sexuality in general prior to the course. The course built on their knowledge and highlighted the importance of considering LGB people and their needs.

Evaluation Interview 3

Female, 50s, Hospice

What was your personal experience of the training?

Excellent. Enjoyed the whole session. A little short and this indicates the interest in the topic and the way it was presented. Found it was great to have a variety of people from different disciplines at the session. Openness of the presenter added to the ambience and content of the session.

What effect, if any, has the training had on you professionally?

First of all it created my awareness of the LGB issues. While it was something that I had thought about, I had never really encountered it openly. Having attended the session, I am now more aware of the skills that I need to address the issues. I particularly found the 5 steps for best practice and example of “inclusive questions” invaluable and they will be grounds for approaching the subject.

What effect, if any, has the training had on care provision to LGB patients in your service?

It can only improve it. It has also raised awareness of the importance of being comfortable and open to discuss sexuality issues with patients and how best that questions can be answered. Multi-disciplinary team awareness will also be increased and improved, so that all the training will ultimately result in better practice and better care for patients, particularly at this time of their lives. Ireland has a long history of shunning the topic, and I feel that having attended the training, it can be “brought out into the open” more – especially at this precious time of the patient’s life. Also keeping the environment safe for patients to talk about those issues is important and the training will only help staff to create this safe environment.

What effect, if any, has the training had on the organization where you work?

A bit soon to say as yet, because it has been so recent. It can only have a positive impact as now there is more awareness of the issues encountered by this group of people.

Is there anything else you would like to say about the training?

Finn was excellent—a wonderful presenter. Really knows what he is talking about. I suggest that it is made clearer the meaning of gay, lesbian, bisexual and transgender—so that it is not assumed that those there at the training session know the meaning of each of the terms. People may not be comfortable to ask this question in front of their colleagues.

Evaluator comments

Very open to discussing her feelings about the training. Very positive about the training and would love to see more of it being done—maybe more workshops in the future.

Evaluation Interview 4

Female, 50s, Hospice

What was your personal experience of the training?

I found it very beneficial. I was surprised initially at the idea that it was needed because Ireland has moved on and things are not the way they used to be. But it was very interesting and small ideas such as making literature available to show an awareness of the issues were very interesting.

What effect, if any, has the training had on you professionally?

Again little changes such as the use of “partner” instead of “husband or wife”. Also to ask someone rather than assuming. I was really surprised at self-harm being a part, that younger gay people are so vulnerable to self harm, alcohol, and drug use. I feel that is something to look out for. I feel that cancer and palliative nurses especially are more open and sensitive to the issues anyway. The patients and families would be likely to tell us things they wouldn’t tell other health professionals. Working in family homes gives us more exposure to relationships and the intimate aspects of patients’ lives.

What effect, if any, has the training had on care provision to LGB patients in your service?

I can’t say off hand. The training has been very recent and I haven’t taken on any new patients in that time but I suppose future patients might experience me as more open and as making fewer presumptions.

What effect, if any, has the training had on the organisation where you work?

I would be surprised if it has had a large effect as I feel that that they are open and accepting anyway. Finn suggested putting up literature but there is a policy here that they don’t put much literature up which may be a barrier to that suggestion. We don’t put up stuff about death and dying.

Is there anything else you would like to say about the training?

I attended with two colleagues and found it very enjoyable and interesting. Because it was optional only those who were interested would choose to attend so probably those who need it don’t go. I found Finn to be an extremely good presenter, really articulate and open. I wouldn’t suggest any changes or anything.

Evaluator comments

The participant appeared to be open and honest in her evaluation. She repeatedly referred to the close nature of her work with patients and did not appear to have any sense that patients might conceal issues of sexuality from her. In that way, while she found the training delivery and content excellent, I would query the extent to which she feels it truly applies to her. It would be interesting to perhaps have a gay service user participate in the training who might share their story regarding their experience. Perhaps this might help to cement the idea that this issue is real and occurs in all aspects of healthcare including palliative care at home.

The trainer's experience

Dr. Reygan holds a PhD in LGBTQ Psychology and specialises in research and training on gender and sexual minorities. He said the following about the project:

As an LGBT-identified person the experience of developing and delivering the training presented challenges both professional and personal. One of the salient characteristics of LGBT-related research and training is the fact that researchers and educators are often, though not always, LGBT-identified. In this regards I embodied a dual role, being both the trainer and a member of this minority group, and this situation presents both advantages and disadvantages: on a professional level I was familiar with the literature on the healthcare needs of LGBT populations and I had spent many years working and living in LGBT communities both in Ireland and abroad. In this sense the literature and knowledge base in the area was something that was also part of my own personal experience. In this regard, during the trainings I found that appropriate and sensitive disclosure of particular life events and experiences related to being LGBT were well received by participants. This personal narrative appeared to bring greater insight and understanding on the realities of LGBT peoples' lives. In short, the overlap between the professional and the personal appeared to enhance the quality of the training in a number of different ways.

Being the trainer and LGBT-identified also presented challenges. For example, it became evident during the course of the training that healthcare staff generally had very little or no training in the area of sexual and gender minority populations and these populations' healthcare needs. Participants presented unelaborated thoughts, ideas, biases and feelings about LGBT populations and the trainings offered them the opportunity to discuss some of these ideas for the first time. While this process of engagement was reported by participants to have been a positive one, I at times found it challenging to listen to some of the ideas and opinions that emerged.

Overall the experience of developing and delivering the training was satisfying on both a professional and personal level. Given the relatively recent decriminalisation of homosexuality in Ireland and the passing only in 2010 of the Civil Partnership Act, it was encouraging to be invited to deliver this training. That the Irish Hospice Foundation, the Irish Cancer Society and the Health Service Executive funded this initiative is an indication of how much Ireland has progressed in recent years in terms of equality for LGBT people. While much work remains to be done in educating our health and social care professionals, it was heartening to see an attitude of general openness and inclusivity expressed by participants.

Conclusion

Education programmes already exist in Ireland on a range of LGB issues, including the work of BeLonG To (see www.belongto.org) which educates staff in the Irish school system on how best to work with issues of sexual orientation and gender identity. In the United States, the National LGBT Cancer Network (www.cancer-network.org) provides training in New York on cancer among LGBT populations that is tailored to the needs of service providers and hospitals. Nevertheless the present project was the first of its kind in Ireland to train health and social care staff on providing oncology and palliative care to LGB patients. Few such projects of this kind exist internationally and the project may be seen as a model of best practice both in Ireland and abroad. The project emerged in the context of a changed cultural climate in Ireland that included the introduction of comprehensive equality legislation as well as the passing of the Civil Partnership Act (2010). The guidelines of the professional bodies on providing care to LGB patients, as well as the HSE's inclusion of sexual orientation in its Patient Charter, also point to the gradual mainstreaming of the needs of LGB populations in the Irish healthcare system. In this context the project developed a training programme for staff from a wide range of disciplines in both acute hospital and hospice settings and supported palliative and oncology care staff to deliver affirmative care to their LGB patients, partners and families. A number of limitations of the training were apparent and these included its brevity which at 50 minutes did not allow participants to further explore the topic. Also, the long term outcomes of the training for practice were beyond the remit of the project. Nevertheless the training was positively received by participants, the overwhelming majority of whom requested both further training in the area and the roll-out of the training across the health services and at postgraduate level.

Findings from the evaluation of the project highlighted participants' different levels of comfort and familiarity with LGB issues. For example, one interviewee felt that more information could be presented during the training while another believed that there was too much information. Overall staff became more aware of LGB issues during the course of the training and it is hoped that the outputs from the project will change the experience of oncology and palliative care among LGB patients and families. In this sense the materials generated for the training form a substantive platform from which further training, in a variety of formats, can be delivered. In this regard, the training materials are available free of charge to all hospitals and palliative care settings in Ireland. Furthermore through the publication of the report on Lenus and through publication and presentation in the international arena—such as at the American Psychological Association (APA) annual conference in 2011—the project is contributing to a growing body of knowledge about the health care needs of LGB people in Ireland and globally. Consequently it is hoped that educators who provide the training in the future will either be LGBT-identified or have expertise in the needs of LGBT populations and, if this is not possible, will require training in the delivery of the programme so as to maintain its success.

A number of issues arose during the course of the study. Firstly, the interest in the training on the part of healthcare providers was notable and there was a palpable shift in the attitudes of participants in the course of the trainings. Staff became aware of their educational and service gaps and in the process became more aware of and interested in the needs of LGB patients. Secondly, a number of participants in the different sites queried the absence of transgender issues. The decision not to focus on transgender issues was taken so as to avoid tokenism and because transsexual populations present with specific clinical needs. Nevertheless some mention was made of transgender terminology and related healthcare issues and participants were referred to relevant resources.

Overall the large number of staff who participated in the trainings and the enthusiasm with which they engaged with the topic point to the desire on the part of healthcare staff to learn about the lives and healthcare needs of LGB patients in Ireland. The openness of healthcare providers and their desire to provide optimal care to their minority group patients was apparent during the trainings. This attitude of inclusivity and awareness of diversity reflects the changing nature of Irish society and is in line with the guidelines of the professional bodies. The general call from participants that the training be rolled out nationwide merits attention.

Recommendations

It is clear from the findings of this study that the delivery of specialist training in the area of LGB issues in oncology and palliative care was well received. The training filled an identified gap in service competency and capacity. The training programme demonstrated that such education is needed and valued. Whilst the lunchtime format was effective, participants requested opportunities for further learning and discussion of the issues raised. Whilst acknowledging that this pilot programme did not include transgender issues in its content, the steering group strongly recommend further specialist training for oncology and palliative health care staff specifically to address the needs of transgendered people. Therefore, on the basis of this knowledge and experience, the steering group recommend the following:

→ Improve Public Profile of LGB Issues in Healthcare

A collaborative effort is required to increase public awareness of the need to deliver equitable service to LGB patients and their families in oncology, palliative and other healthcare environments. This is the responsibility of all agencies who provide care to patients.

The provision of information on websites and in leaflets naming the unique issues that LGB patients face, including a list of support and care available would address some of the gaps in service provision.

Public discourse of the unmet needs of LGB patients and their carers would help to challenge the attitudes, prejudice and bias that prevails in society.

→ Name LGB People in Policy and Procedures

Healthcare providers need to openly state the inclusiveness of their services for minority groups. This statement should be prominently displayed in waiting rooms. Diversity policies should make specific reference to the LGB community.

Practice and Care guidelines need to demonstrate inclusiveness by naming the LGB issues that must be considered when providing care to patients. This should include the use of appropriate language and terminology.

Clear feedback and complaints policies should be in place so that LGB patients and their carers can provide feedback on service they are unhappy with.

→ Ensure Programmes and Services are LGB-Inclusive

There needs to be recognition of LGB issues in bereavement support both before and after death.

All service providers should have basic sensitivity training around LGB issues.

On-going engagement with the LGB community is needed to encourage and enable openness within services, thus building belief and confidence that services are addressing the needs of their LGB clients.

Publication and promotion of specific programmes or services aimed at LGBT patient and/or carer community.

Keep LGB literature available in the service, in waiting rooms, in literature stands and on wards. Where written material is available, it should include reference to loss of same-sex partner and issues for gay and lesbian couples.

The LGB community should be involved in consultation on the design, delivery and evaluation of services to ensure equity of access and care.

→ **Include LGB Issues in Professional Training and Development**

Training should be available in a variety of formats to ensure the broadest reach to healthcare professionals in all disciplines such as e-learning and supported distance learning.

Awareness of LGBT issues and needs should be embedded in health care undergraduate and post graduate training programmes.

The Irish Cancer Society and the Irish Hospice Foundation are committed to ensuring these recommendations are implemented.

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Appendix A
Participant Information Leaflet
Informed Consent Form

Participant Information Leaflet

The development of best practice guidelines and a pilot training programme for health and social care professionals providing palliative and oncological care to lesbian, gay and bisexual (LGB) patients

You are being asked to participate in a staff training module and its evaluation which are taking place in a number of hospitals and hospices in the Dublin area. This training is for palliative and oncology care staff who provide care to individuals who are lesbian, gay or bisexual (LGB) and who interact with the partners and families of LGB patients in a care setting. The training aims to support you in delivering LGB affirmative care to your LGB patients and in interacting with the partners and families of LGB patients in an affirmative way. The training also aims to increase your awareness of LGB issues relevant to help-seeking behaviours in hospital and hospice settings and to provide you with access to training materials.

You are being asked to participate in this training module because you are a staff member. If you agree to participate in the training it will take place at a time that is convenient for you and will last approximately 50 minutes. The training will provide you with information about the issues that LGB patients face in oncological and palliative care settings and guidelines on how best to provide care to your LGB patients. It is hoped that participation in the training module will enhance your knowledge, skills and competencies in providing care to your LGB patients. You are also being asked to participate in a brief evaluation of the training.

The evaluation has two components both of which are optional. The first component of the evaluation is a brief questionnaire that you will be asked to complete at the end of the training module. The second component of the evaluation is an interview about your experiences of the training module. Only a small number of participants are required to participate in this second component of the evaluation. If you agree to participate in an interview it will last approximately 30 minutes and will take place at a time that is convenient for you. If you decide to participate in the training or in either component of the training evaluation your feedback on the training may be used in future presentations and publications. However all identifying information will be removed from your feedback, your identity will remain confidential, your name will not be published and will not be disclosed to anyone outside the training group.

If you decide to volunteer to participate in this training and its evaluation, you may withdraw at any time. The training and its evaluation have received approval from the health care settings in Dublin where the training is taking place. You can get more information or answers to your questions about the training and its evaluation, your participation and your rights from Dr. Paul D'Alton (P.D'Alton@st-vincent.ie) or Dr. Finn Reygan (F.Reygan@st-vincent.ie). If the training team learns of important new information that might affect your desire to remain in the training and its evaluation, you will be informed at once.

Informed Consent Form

The development of best practice guidelines and a pilot training programme for health and social care professionals providing palliative and oncological care to lesbian, gay and bisexual (LGB) patients.

Principal Investigator:
Dr. Paul D'Alton,
Head of Dept. of Psycho-oncology,
St. Vincent's University Hospital,
Elm Park, Dublin 4

Researcher:
Dr. Finn Reygan,
Dept. of Psycho-oncology,
St. Vincent's University Hospital,
Elm Park, Dublin 4

Study background

You are being asked to participate in a staff training module and its evaluation which are taking place in a number of hospitals and hospices in the Dublin area. This training is for palliative and oncology care staff who provide care to individuals who are lesbian, gay or bisexual (LGB) and who interact with the partners and families of LGB patients in a care setting. The training aims to support you in delivering LGB affirmative care to your LGB patients and in interacting with the partners and families of LGB patients in an affirmative way. The training also aims to increase your awareness of LGB issues and to provide you with access to training materials. Your participation in the training and its evaluation is confidential and your name will not be disclosed to anyone outside the training group.

Declaration

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME:.....

CONTACT DETAILS:.....

PARTICIPANT'S SIGNATURE:.....

DATE:.....

Statement of researcher's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHER'S SIGNATURE:.....

DATE:.....

Appendix B

Training evaluation forms

We are interested in your experience of the training you participated in today. Thank you for answering the following questions as quickly and accurately as you can.

1. What is your profession (doctor, nurse etc.)?

2. What age are you? 18-29

30-39

40-49

50-59

60+

3. What is your gender? Male Female Trans

4. How would you rate:

4.1 Your overall knowledge of the topic covered in the training

Before training	Low	Medium	High
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After training	Low	Medium	High
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4.2 Your confidence in providing care to LGB patients

Before training	Low	Medium	High
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After training	Low	Medium	High
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4.3 Your comfort using the terms lesbian/gay/bisexual/LGB

Before training	Low	Medium	High
-----------------	-----	--------	------

High

Poor

- No

- No

- No

- No

-
-

-
-

Project title

The development of best practice guidelines and a pilot training programme for health and social care professionals providing palliative and oncological care to lesbian, gay and bisexual (LGB) patients

Training evaluation form

Thank you for taking the time to complete this evaluation of the above training. Please fill out the form below and return it with a one or two page report including quotes from participants to: F.Reygan@st-vincent.ie. Your evaluation will be included unaltered in the final report on the project.

Evaluator's name:

Interview site:

Date of evaluation:

Participant's gender: Male Female Trans

Participant's profession:

Participant's age: 18-29
 30-39
 40-49
 50-59
 60-69

Please follow the outline of this interview schedule:

- What was your personal experience of the training?
- What effect, if any, has the training had on you professionally?
- What effect, if any, has the training had on care provision to LGB patients in your service?
- What effect, if any, has the training had on the organisation where you work?

- Is there anything else you would like to say about the training?

Evaluator comments:

.....

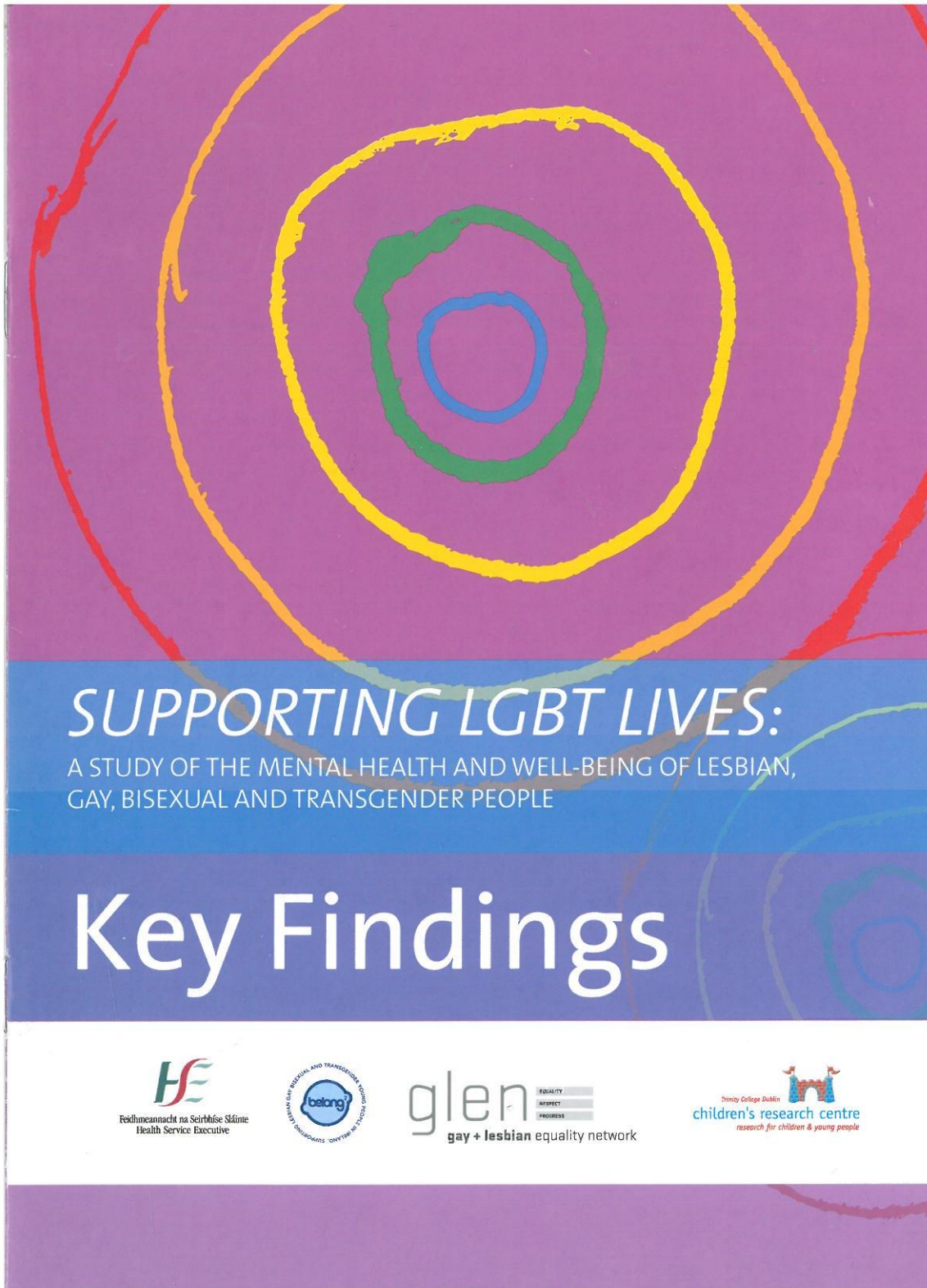
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Appendix C

Training handout



The image shows the front cover of a booklet. The top section is a solid green horizontal band. Below this, the main background is a vibrant blue. Overlaid on the blue background are several concentric, curved lines in varying shades of blue, creating a sense of depth and movement. The title is written in a white, bold, sans-serif font with a slight drop shadow, making it stand out against the blue background. The text is arranged in four lines: 'Coping with the', 'death of your', 'Same-Sex', and 'partner'.

Coping with the death of your Same-Sex partner

Information for lesbian,
gay and bi-sexual people

Publications included in handout

Mayock, P., Bryan, A., Carr, N., & Kitching, K. (2009). Supporting LGBT lives: A study of the mental health and well-being of lesbian, gay, bisexual and transgender people. Dublin: GLEN and BeLong to Youth. (see p. 45)

Irish Hospice Foundation/GLEN (2009). Coping with the death of your same-sex partner. Information for lesbian, gay and bisexual people. Bereavement leaflets Series D, 1. Irish Hospice Foundation Bereavement Resource Centre/GLEN. (see p. 46)

Almack, K. (2007). End-of-life needs of lesbian, gay and bisexual older people. End of Life Care, 1(2), 27-32.

Katz, A. (2009). Gay and lesbian patients with cancer. Oncology Nursing Forum, 36(2), 203-207.

Inclusive practice statement

This practice values the dignity of all patients and does not discriminate on the basis of gender, marital status, family status, age, disability, race, nationality, sexual orientation or religious belief.

Appendix D

Core training module

6/1/2011

Good practice with lesbian, gay and bisexual (LGB) patients

Finn CO Roygan

Do you work with lesbian, gay or bisexual (LGB) patients?

LGB voices

"I remember people saying to me, 'You've lost a good friend', and I felt something almost sinking in my head and thinking, I almost exploded, because I thought, 'I haven't lost a friend, I've lost someone that's been part of my life for 22 years, since I was 12. And 22 years down the road, I've lost this person'. And I mean together for 22 years, so it's a huge amount... everyone has their ups and downs, but 22 years down the road, we were still together and I thought this friend, I haven't lost a friend. Yes, I've lost a friend, but I have lost 22 much more, and I actually remember thinking, 'You've no idea!'" (Bustin & Higgins, 2008)

Background

Irish College General Practitioners

Irish Institute of Mental Health Nursing

Gay and Lesbian Equality Network

(Equality Legislation/Civil Partnership Act 2010)

HSE Patient Charter

You can expect care that respects your culture, beliefs, values and other characteristics such as your age and gender, sexual orientation, faith, political beliefs or disability...

Funding bodies

Irish Hospice Foundation

Irish Cancer Society

Health Service Executive

1

Training outline

- Language use
- Irish research
- LGB oncological and palliative care
- 5 steps to best practice

Aims and objectives

- Culturally competent care: a learnable skill
- Small changes make a big difference

Terminology



Terminology

LGB: lesbian, gay, bisexual

LGB(t): lesbian, gay, bisexual, transgender

Language use

- Lesbian women: romantically, sexually and/or emotionally attracted to women
- Gay men: attracted to men
- Bisexual people: attracted to people of both sexes

Language use (cont'd)

- 'Gay': LGB people generally
- 'Straight': heterosexual

Language use (cont'd)

- Sexual orientations: hetero-, homo-, bisexual
- 'Homosexual': negative

Language use (cont'd)

- Coming out
Self-discovery → Self-acceptance → Disclosure
- Homophobia
Prejudice/Stereotyping/Discrimination

LGB health

- LGBs are diverse populations
 - ▷ Sex
 - ▷ Social class
 - ▷ Age
 - ▷ Ethnicity
 - ▷ Disability

Irish research

- Supporting LGBT Lives (2009)
- N=1100, online survey
- LGBT healthcare problematic

Supporting LGBT Lives (2009)

- ↓ provider cultural competence
 - ▷ Professional framework
 - ▷ LGBT relevance to work/life/health?
 - ▷ Impact of homophobia on physical/mental health?
 - ▷ Specific health risks/challenges of LGBT?

Supporting LGBT Lives (2009)

- 77% felt healthcare professionals needed more knowledge/sensitivity
- Minority stress
 - ↑ Psychological distress
 - ↑ Suicidal behaviour/self-harm
 - ↑ Depression/anxiety/substance use

Supporting LGBT Lives (2009)

- 45% sought LGBT-friendly professionals due to previous negative experiences
- 40% felt respected by healthcare provider

Supporting LGBT Lives (2009)

- 27% self-harmed
- 18% attempted suicide
➢ ↑ risk LGBT youth
- 28% hid sexuality

Supporting LGBT Lives (2009)

In absence of training in Ireland: wide variation in quality of care provision to LGBTs

Legal requirements

- Equal Status Acts 2000/2004
➢ Prohibit discrimination in health services
- Civil partnership legislation 2010
➢ Spouses/civil partners treated equally

LGBT oncology

Lesbian women

- ↓ contraceptive use
- ↑ nulliparity
- ↑ overweight
- ↓ screening
- ↑ ovarian cancer
- ↑ breast cancer

Quinlan (2008)

LGBT oncology

Men who have sex with men (MSM)

- ↑ HIV/AIDS
- ↑ HPV
- ↑ anal cancer

Walden et al. (2011)

LGBT oncology

40% OC/PL patients psychological distress

+

LGBs ↑ depression/anxiety

LGB(T) palliative care

* Suboptimal care

- Presumed heterosexuality
- Lack of awareness of same-sex relationships
- Homophobia

Almeida et al. (2010)

LGB(T) palliative care

* Older LGB(T) cohorts

- ↑ living alone
- ↓ out
- "Hidden" relationships/forced disclosure
- ↓ family-of-origin support
- Support networks invisible

LGB(T) palliative care

* Disenfranchised grief

- Relationship not seen
- No active role in care of dying
- Grief unacknowledged/diminished

Higgins and Buxton (2008)

5 steps to best practice with LGB patients



Step 1

Stay informed on LGB issues and stressors

Step 2

Don't assume all patients are heterosexual

Step 2 Don't assume

- * You already have LGBT patients
- * Patients may not be 'out'
 - > Married
 - > Religious order
 - > Homophobia (such as at work)

Step 2 Don't assume

- * Divorced families
 - > Same-sex couples +/- children
 - > Straight couples + LGBT children
 - > Children + LGBT parents
- * Non-judgemental

Step 2 Don't assume

- * Hinting at sexual orientation
- * Ask open and inclusive questions

Step 2 Don't assume



Step 3

Respond positively when patients disclose they are LGBT

Step 3 Respond positively

- Coming out is an important time
- Be supportive

Step 3 Respond positively

How can the team help you manage this?

What can we do to help you get through treatment?

Step 4

Challenge anti-gay bias and take a gay-affirmative approach

Step 4 Challenge anti-gay bias

- Take a gay-affirmative approach
 - Normal/positive variant of human sexuality
 - LGBs satisfying lives/committed relationships/families
 - Challenge LGB stigmatization

Step 5

Demonstrate that your practice is inclusive of LGB people

Step 5 LGB-inclusive practice

- Use LGB-inclusive language
 - Paperwork/magazines
 - Community referrals/links
 - Office statement

6/1/2011

5 steps to best practice with LGB patients

Step 1: Stay informed on LGB health issues

Step 2: Don't assume all patients are heterosexual

Step 3: Respond positively when patients disclose they are LGB

Step 4: Challenge stigmatizing bias and take an affirming approach

Step 5: Demonstrate that your practice is inclusive of LGB people

Handout

- 5 steps to best practice with LGB patients
- Examples of inclusive questions
- Further information and links