

Advances in End of Life Care

Third Annual Research Symposium (also via Webinar)

HOSPICE SEMINAR ROOM | 26 FEBRUARY 2021 | 9:30AM - 12:30PM



Welcome



Anne Mills

**Director of the Scholl
Academic Centre**

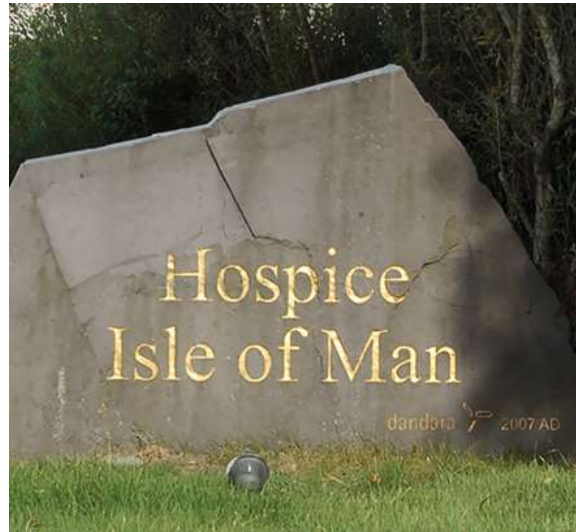
Chair



Professor John Ellershaw
Professor of Palliative Medicine,
University of Liverpool

Director of Palliative Care
Institute Liverpool

Clinical Director, Academic
Palliative and End of Life Care
Centre, Liverpool & Broadgreen
University Hospitals NHS Trust



SACCESSful? A review

On behalf of the
Academic Research
Team,
Scholl Academic Centre

February 26th 2021



**Today we celebrate three years of academic research in
Hospice Isle of Man**

but the foundations began in 2017

DUSTIN HOFFMAN

RENE RUSSO

MORGAN FREEMAN

OUTBREAK

Island

The world in 2017

Ageing population

Increasing referrals to Hospice

Uncertain level of need among population

Need for evidence, but lack of data



16,000 WANT MONEY BACK

Company boss David

A provisional liquidator has

Ramsey Commissioners will consider making a formal offer to buy Ramsey Court House and the grounds when the board meets this week. See page 8

Prisoners could be given e-cigarettes

Inmates at Harty prison are to be allowed to use specialist e-cigarettes as a part of a six-month pilot project, if Tyrnold gives the go-ahead. See page 12

Unlicensed driver smashes into car



Funding from
Manx Lottery Fund
Gough Ritchie & Helen
Clucas Charitable Trusts



Funding from
Dr Scholl Foundation

Lymphoedema
service review

May
2017

Research
Fellow joined

Listening
Projects

March
2018

Director of
Research
joined

Needs
assessment

May
2018

2 Research
Assistants joined



Scholl Academic Centre Launch, 2018

“We are happy to hear that you are making such great strides in the areas of hospice and palliative care.”

Ms. Pamela Scholl,
President of the Dr. Scholl Foundation



Professor
Aine Carroll,
University College
Dublin



Professor
Gunn Grande,
University of
Manchester



Professor Irene Higginson,
Cicely Saunders Institute
King's College London



祝福 to Scholl Academic Centre

Greetings from the Hong Kong Jockey Club Integrated Cancer Centre (HKJICC)



International Foundation
for Integrated Care
IFIC Scotland



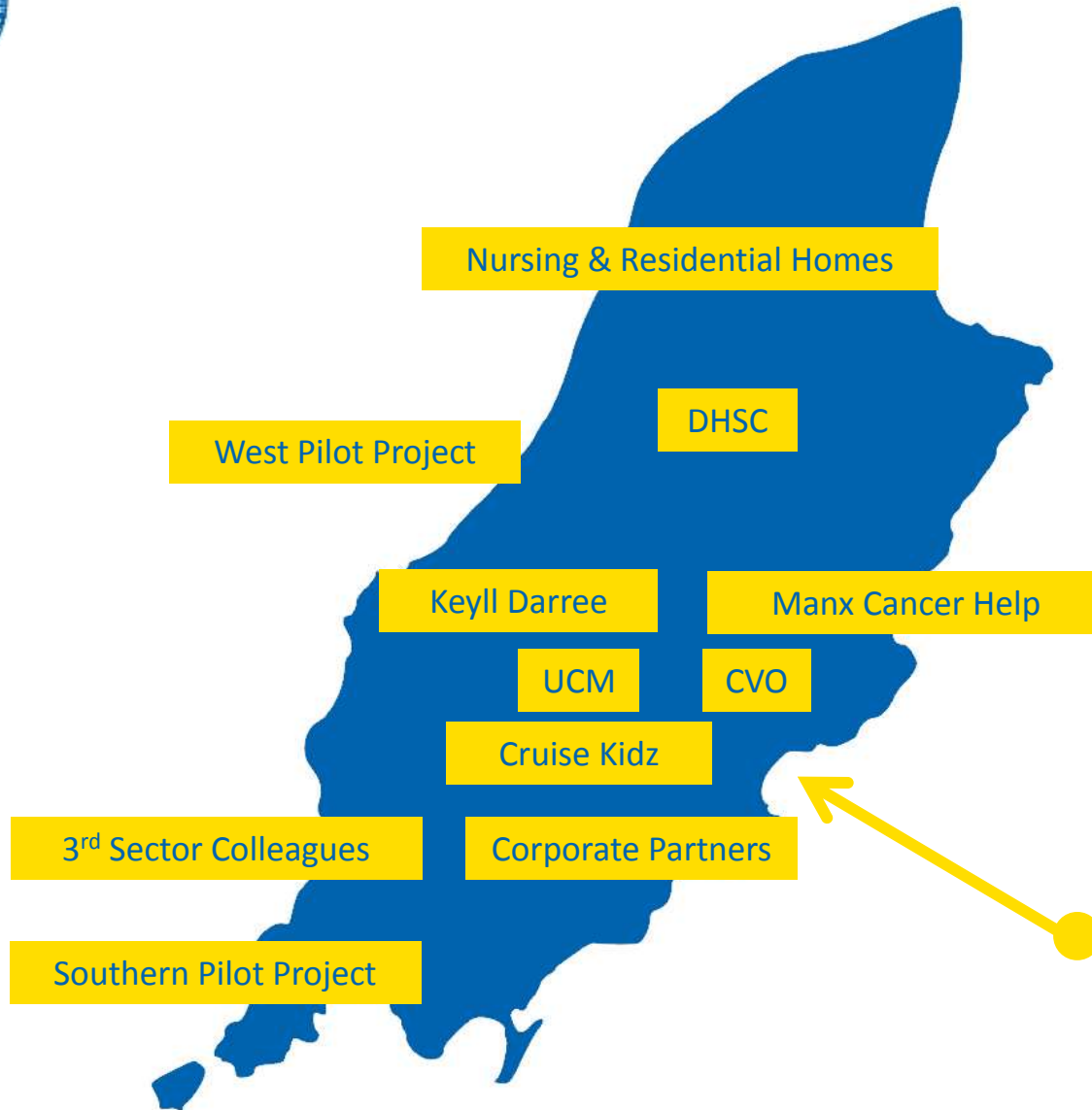
Prof. Anne Hendry
**Senior Associate,
International Foundation
for Integrated Care (IFIC)
Director IFIC Scotland**



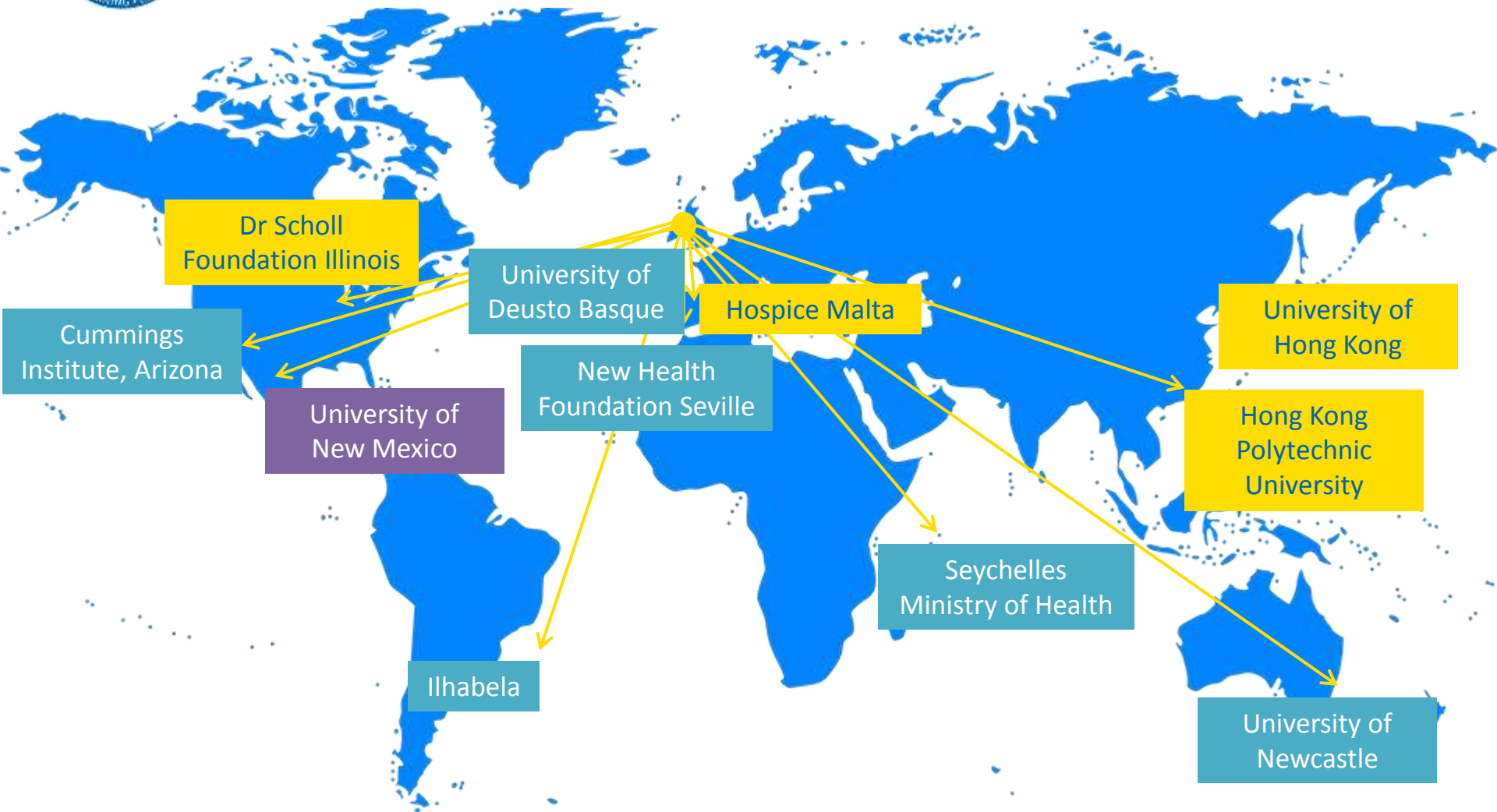
Mandy Andrew
**IFIC Senior Associate,
Associate Director, the Health and
Social Care Alliance Scotland**



Marie Curran
**IFIC Scotland Coordinator –
Communication, Webinars and
Special Interest Groups**





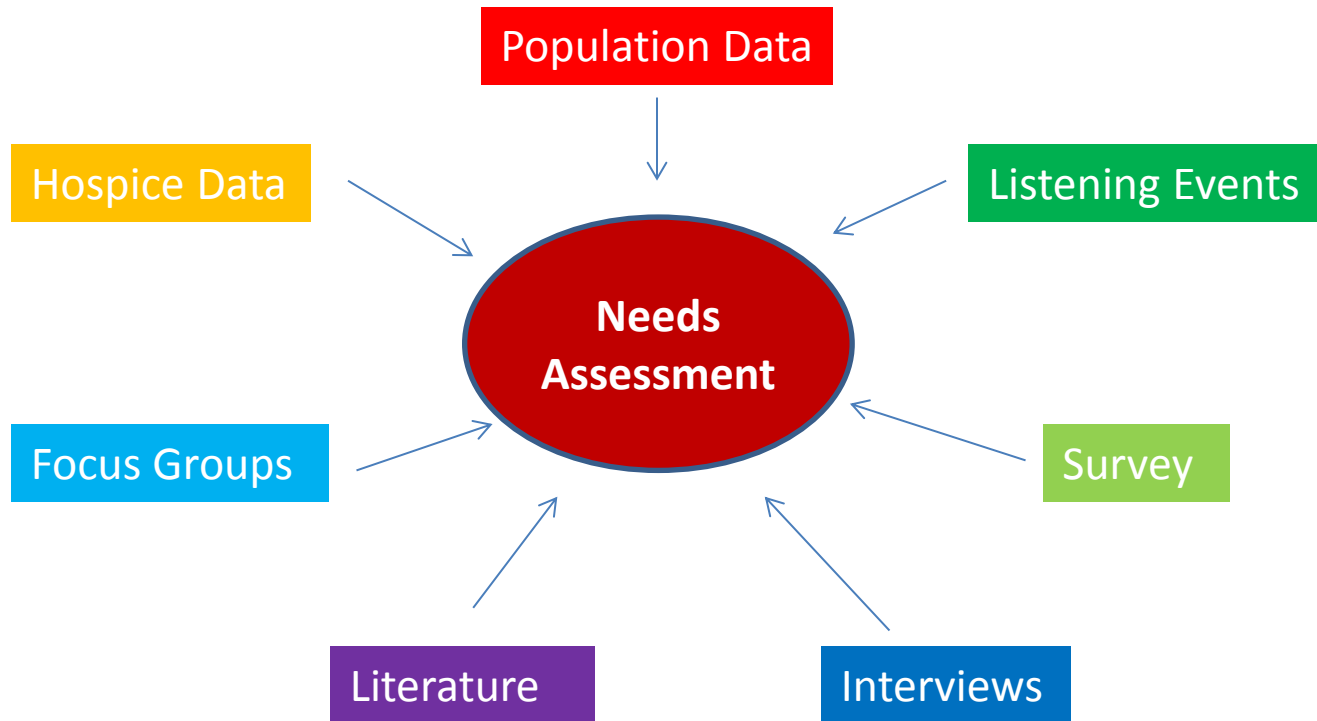




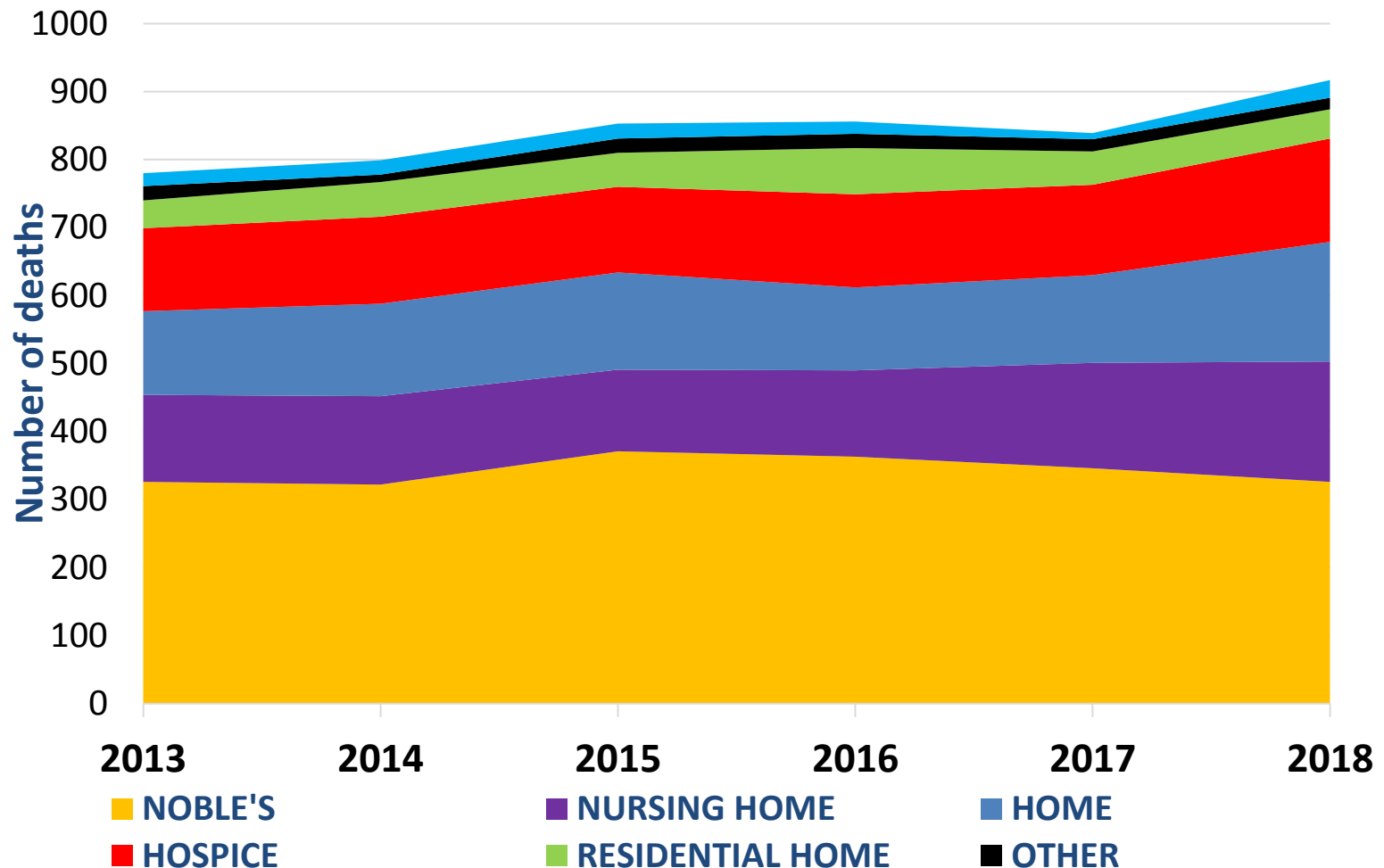
Where are we now?

**We have an evidence base of information derived
from local data & respondents**

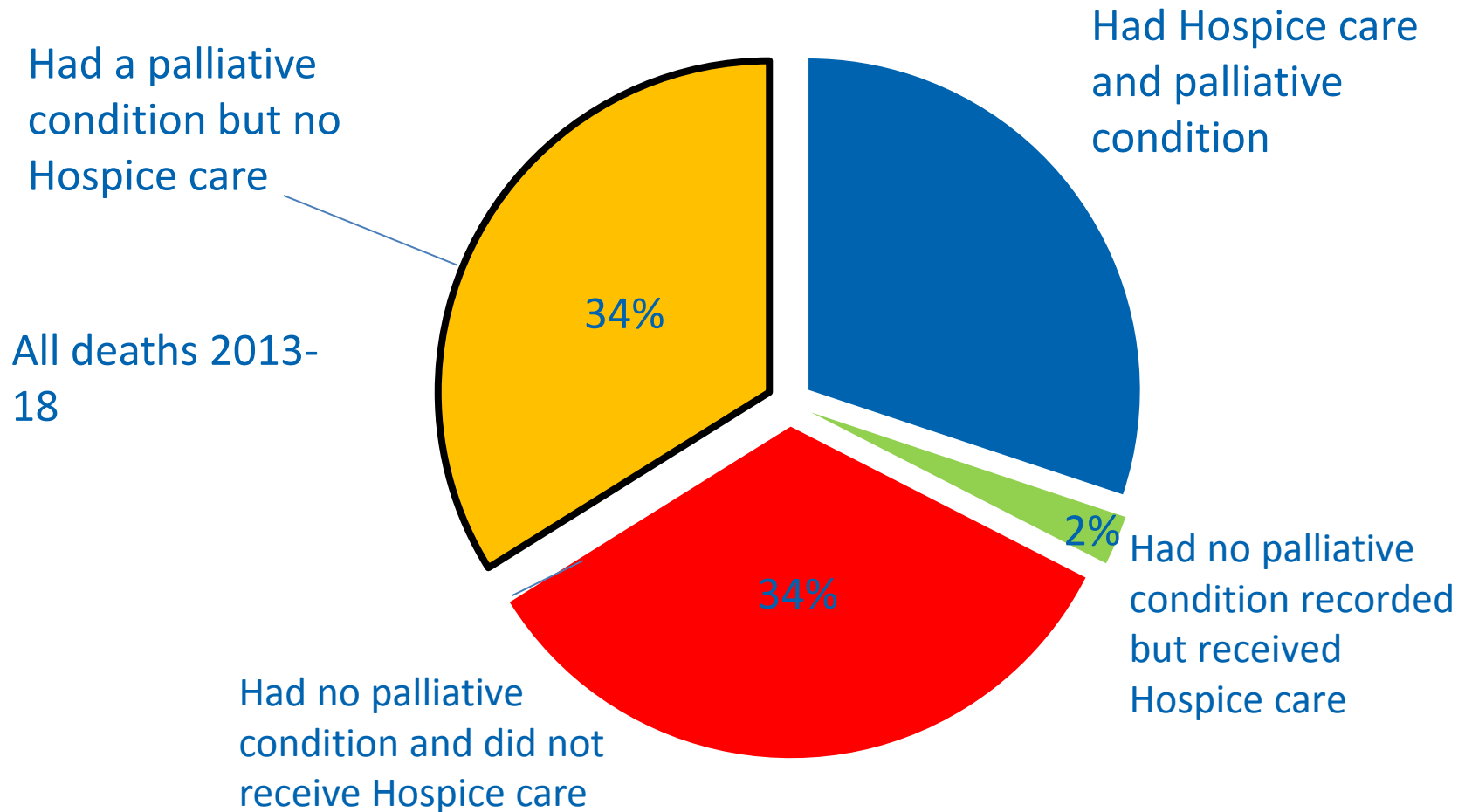
The data sources for the needs assessment



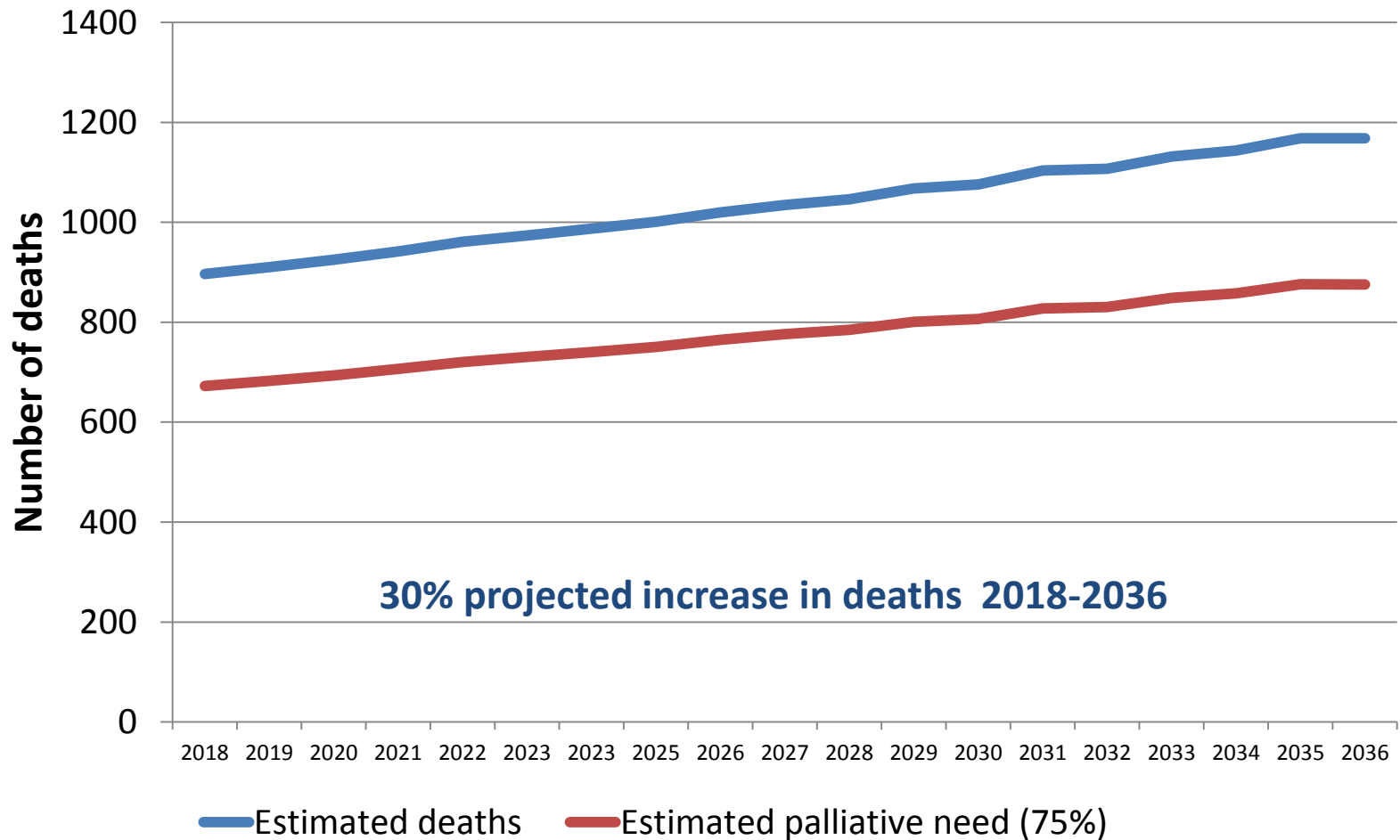
Where do people die?



Who is/is not receiving palliative care?

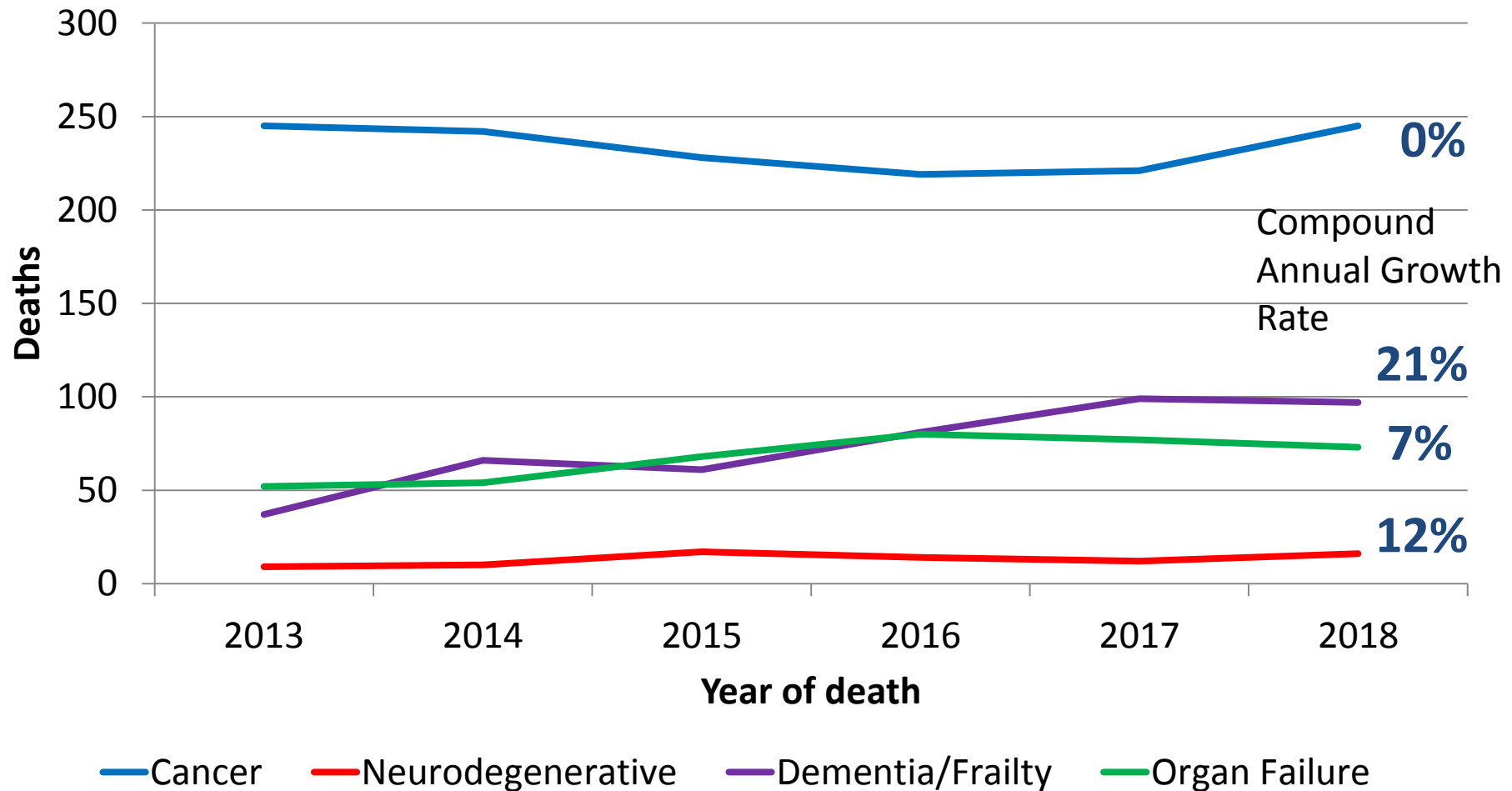


Who will need care in the future?





What conditions will we be caring for?



Evaluation of innovations in progress

Compassionate Isle of Man

Draft Evaluation Plan Version 1

OBJECTIVE 1: To create community connections

Outcome measures:

- Products of Network collaboration
 - Number of Sit and Chat benches/lanyard users or (better) impact of use benches/lanyards
 - Impact of World Kindness Day/Dying Matters week activities
 - Impact of Café Connect

Measured by:

- Stories collected from bench and lanyard users or organisations they have impacted
- ?Responses to specific questionnaires about benches/lanyards, WKD/DM week

Project ECHO Evaluation presented as a logic model

1. Resources/ inputs	2. Activities	3. Outputs	4. Short-term outcomes	5. Long-term outcomes
Funding	No. of participants recruited	Curriculum	Changes in measured confidence and skills	Improved care
Staff in Hub	Curriculum engagement	Materials produced	Changes in perceived confidence and skills	Patient family satisfaction
Materials provided	No. of sessions	No. participants attended sessions	Perceived changes in knowledge	More achievements preferred
	No. of specialist presentations	No. who attend all sessions	Perceptions of support	Better resources
	No. of cases discussed	Recommended changes in practice	Changes in practice	

Columns 1, 2 and 3 will be assessed by reviewing the data on sessions, attendees and materials. Added to this we have the feedback from the survey on how the sessions went, any problems encountered and their solutions. To supplement this we propose follow-up sessions with initial participating groups (Nursing Homes) to ask for their feedback on the process, the curriculum, the supporting materials and any suggested improvements.

Column 4, short-term outcomes has a number of measurement methods.

Changes in measured confidence and skills: The End of life skills questionnaire has been distributed to ... and ... completed replies have been obtained. We have the opportunity to re-administer at least some of the Nursing Homes. This will not increase the baseline data but should still be assessing the overall level of skills and confidence within this sector. For future participants this will be an essential part of the registration process. We will simplify it as much as possible.



Understanding the experience of all end of life care on the Island

For Registry use only

Entry No.

Please Circle

Registry: Douglas Castletown Ramsey Peel

Questionnaire on the Experience of End of Life Care on the Isle of Man

We would like to ask you a few questions about your recent experience of the end of life care for a loved one.

It would be very helpful if we could link your responses to the cause of death of your loved one.

Please tick here if you prefer that we **DO NOT** do that.

☐

Integrated care: A case study

David M. Atkinson
 Senior, Vice President, Senior Advisor



Abstract
 Integrated care is a concept that encompasses the integration of health care services across the continuum of care, from prevention to end-of-life care. This paper describes the experience of the University of Michigan Health System in implementing integrated care across its various settings, including primary care, specialty care, and long-term care. The paper discusses the challenges of implementing integrated care and the benefits that can be realized. The paper also describes the role of the senior advisor in implementing integrated care.

Keywords
 Integrated care, senior advisor, health system, primary care, specialty care, long-term care.

Introduction
 Integrated care is a concept that encompasses the integration of health care services across the continuum of care, from prevention to end-of-life care. This paper describes the experience of the University of Michigan Health System in implementing integrated care across its various settings, including primary care, specialty care, and long-term care. The paper discusses the challenges of implementing integrated care and the benefits that can be realized. The paper also describes the role of the senior advisor in implementing integrated care.

Background
 Integrated care is a concept that encompasses the integration of health care services across the continuum of care, from prevention to end-of-life care. This paper describes the experience of the University of Michigan Health System in implementing integrated care across its various settings, including primary care, specialty care, and long-term care. The paper discusses the challenges of implementing integrated care and the benefits that can be realized. The paper also describes the role of the senior advisor in implementing integrated care.

Conclusion
 Integrated care is a concept that encompasses the integration of health care services across the continuum of care, from prevention to end-of-life care. This paper describes the experience of the University of Michigan Health System in implementing integrated care across its various settings, including primary care, specialty care, and long-term care. The paper discusses the challenges of implementing integrated care and the benefits that can be realized. The paper also describes the role of the senior advisor in implementing integrated care.

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The current issue and full text archive of this journal is available on Emerald insight at:
<http://www.emerald.com/insight/1473-9018.htm>

Case study method to design and evaluate person-centred integrated palliative and end-of-life care

Giovanna I. Cruz and Sarah M. McGhee
Scholl Academic Centre, Hospice Isle of Man, Douglas, UK

Abstract

Purpose – This case study aims to understand the experience of care from a patient/carer perspective and to describe how the method can be replicated to address gaps in evidence relating to integrated person-centred care.

Design/methodology/approach – The case study was constructed using data extracted from personal diaries and medical records kept by a person with a complex condition, correspondence with family from the last 18 months of life and interviews with the care and long-term conditions coordinator. The number of professionals or teams involved in providing care from statutory services, the third sector, and private providers were counted to understand the ecosystem of care. The number of contacts was plotted by provider and purpose of care. The type of care and hours of respite were estimated. A protocol was developed to assess the feasibility of replicating the data and analysis used.

Findings – There were 35 care providers from the public, private and the third sector, demonstrating that only the patient or carer can identify the ecosystem of care. The majority of care was for respite and on average, the carer provided four hours of care per every respite care hour. The method was replicated successfully.

Research limitations/implications – The case study formed the basis of a workshop that brought together health care professionals from the public services and the third sector. The discussions led to the identification of gaps and areas where greater coordination between providers would benefit patients.

Originality/value – The case study method combines companion across patient and care sources of data and health service activity to create a detailed account of care at the end of life. The approach addresses gaps in person-centred evidence for the development and evaluation of integrated palliative and end-of-life care.

Keywords Palliative care; End-of-life care; Needs assessment; Person-centred care; Integrated care; Research methods; Coordinated care.

Paper type Case study

Introduction

Health systems around the world have expressed a commitment to delivering integrated person-centred care e.g. framework on integrated, people-centred health services (Sixty-Ninth World Health Assembly, 2016). While there is a lack of consistency in the literature and in practice as to what constitutes *person-centred integrated care*, the term “person-centred care” is used to describe a range of elements. To name a few, it can refer to how persons are approached (Greenfield *et al.*, 2014) and how they feel (Kulski *et al.*, 2019), the skills and attributes of staff (Coulter and Oldham, 2016) and it is also considered a measure of quality (American Geriatrics Society Expert Panel on Person-Centered Care *et al.*, 2016; Institute of Medicine, 2001). In the context of integrated care, person-centred care contrasts with a disease- and service-centred curative model of care which can result in fragmented care delivered along professional boundaries. Person-centredness is a key organising principle for integrated care (Lloyd and Wait, 2005). An integrated person-centred approach is believed to result in improved patient outcomes, better patient experience and increased satisfaction with care, while improving system efficiencies and reducing costs (World Health Organization, 2015).

Although frameworks of integrated care clearly articulate that the person is at the centre (Layden *et al.*, 2018), the evidence base largely lacks the perspective and voice of the “person” (e.g. patient, carer, family). This criticism has been raised against integrated care

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<http://www.emerald.com/insight/1473-9018.htm>

Listening to action: community involvement in strategy development

Lonan A. Oldam, Giovanna I. Cruz, Sarah M. McGhee, Lottie Morris,
Judi Watson and Anne Mills
Scholl Academic Centre, Hospice Isle of Man, Douglas, Isle of Man

Community
involvement in
strategy
development

Abstract

Purpose – Palliative care requires integration between services, organisations and the community. A series of community engagement programmes named “Listening Events”, were conducted across the Isle of Man. The aim was to involve the community in the development of Hospice strategy by sharing their views on the future of palliative and end-of-life care.

Design/methodology/approach – Three Listening Event programmes were conducted in community settings, secondary schools and the Isle of Man University College. The investigations facilitated discussions on current knowledge of Hospice services, what would matter to people should they need to use these, and how Hospice could best serve the community in the future. Participants and investigators noted thoughts and comments. Data were analysed using thematic analysis.

Findings – In total, 499 people participated from across the community. Main themes surrounded effective care, person-centred care and integrated care. Most themes agreed across the three programmes, despite some nuances.

Originality/value – The results were used as an evidence base for which Hospice Isle of Man’s new strategy was derived in order to ensure that it aligned with the community’s needs. By including conversations and discussions in the community, the Listening Events may have also increased understanding about hospice care.

Keywords Co-production; Hospice; Palliative care; Strategy; Engagement; Community

Paper type Research paper

Background

Integrated care is at the core of the Isle of Man’s Department of Health and Social Care (DHSC) agenda (Isle of Man Government Department of Health and Social Care, Council of Voluntary Organisations and Hospice Isle of Man, 2018). The Isle of Man is a British Crown dependency with a population of 83,000 (Isle of Man Government Economic Affairs, 2017). Hospice Isle of Man is the sole provider of specialist palliative and end of life care on the Island. In 2018, Hospice Isle of Man developed its five-year strategy to fit with the strategic goals of the DHSC strategy in its aim to deliver a person-centred integrated palliative and end of life care service for Island residents (Isle of Man Government Department of Health and Social Care, Council of Voluntary Organisations and Hospice Isle of Man, 2018).

Secular trends evidence an ageing population and increasing multi-morbidity, alongside changes in the main causes of morbidity and death. Across the UK, deaths caused by heart

We would like to offer our thanks to all the members of the public who engaged in the Listening Events and offered their input. Our thanks extend to the supermarkets, churches and schools for their assistance with the Listening Events. This project was supported and funded by the Manx Lottery Trust (an delegated partner of Big Lottery Fund UK), the Gough Rennie Charitable Trust, the Manx Charitable Foundation, and the Elizabeth Charitable Trust, all of whom we express our appreciation. We would also like to acknowledge our colleagues from Hospice Isle of Man for their contribution to the facilitation and organisation of the Listening Events: Dr Hollie Quayle, Lynsey Christian, and Gillian Street.



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Manuscripts in 4 new manuscripts in preparation, led by clinical staff with support of the research team, and many more to come



Mortality Data and the Isle of Man

- Mortality data 2013 and 2019
- Age, sex, marital status, place of death, usual residence, cause of death
- Needs assessment → need for palliative care
 - Cancer, neurodegenerative, organ failure, dementia/frailty
- 34% people who died 2013-2018 had a palliative condition and no Hospice care



Where are we going?

- Who did not receive Hospice care and might have benefited?
- Understanding not everyone with a palliative condition needs specialist Hospice care but Hospice influenced care
- What is the need for specialist vs generalist palliative care?
 - Conditions or indicators of frailty
 - Considering demographics, place of death, usual residence



Thank you

Sarah McGhee

Honorary Professor, Hospice Isle of Man

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Stay in touch, sign up to our newsletter at

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@SACHospiceIOM



Introducing the Outcome Assessment
and Complexity Collaborative (OACC)

KING'S
College
LONDON
University of London

Using outcome measures in palliative care to improve patient care

Cheryl Young
Nurse Consultant
&

Loni Challis
Research Assistant





What are outcome measures?

- Instruments/questionnaires which capture **changes in health status** following healthcare or intervention¹
- **Standardised** and **validated**²
- **Reliable** and **sensitive** in the population of interest²
- Ratings to individual questions often combined to produce an **overall score**²
- **Patient reported** outcome measures: Questionnaires completed by patients to measure their own perceptions of health and wellbeing²
- Used in **audit** (outcomes and quality improvement), **research** (evaluation) and **clinical care** (evidence-based medicine and assessment)^{2,3}



What is already known?

- **Widespread use** and **acceptance**^{3,4}
- **Commissioning** to be based on outcomes rather than activity^{5,6}
- Benefits in **clinical care**: Assessment and monitoring, recording and identification of symptoms, patient involvement and communication, and person-centred care⁴
- **Benefits** identified by **professionals**: Better understanding of patient and family needs, improved quality of care, and assists decision making³
- **Barriers** to use: Time constraints⁴, burden for patient, lack of training, insufficient guidance³, fear of change, and feelings of being assessed⁶
- **Facilitators** for use: Information, guidance and training³, feedback, leadership, and encouragement⁶



Outcome measures in Palliative Care

- Range of outcome measures in palliative care
- The Outcome Assessment and Complexity Collaborative (**OACC**) project selected a suite of measures most suitable for the purpose of capturing outcomes within palliative care services⁵
 - Integrated Palliative care Outcome Scale (IPOS)
 - Australia-modified Karnofsky Performance Status (AKPS)
 - Phase of Illness
 - Views on Care (VoC)
 - Barthel index
 - Zarit carer review



Why did we undertake this study?

- Implementation has proved **challenging and inconsistent**⁶ – despite clear **evidence to support** the use of outcome measures in palliative care
- **Clinician's views** are often **not heard** in outcome measurement³
- Hospice aims to achieve **90%** adoption: **73%** in June 2020
- Numerous **issues** were identified by Hospice clinicians such as uncertainty about the timing of use
- Possible **unknown issues** causing **suboptimal use** and preventing successful implementation⁶
- Barriers need to be **identified in order to be addressed** in future

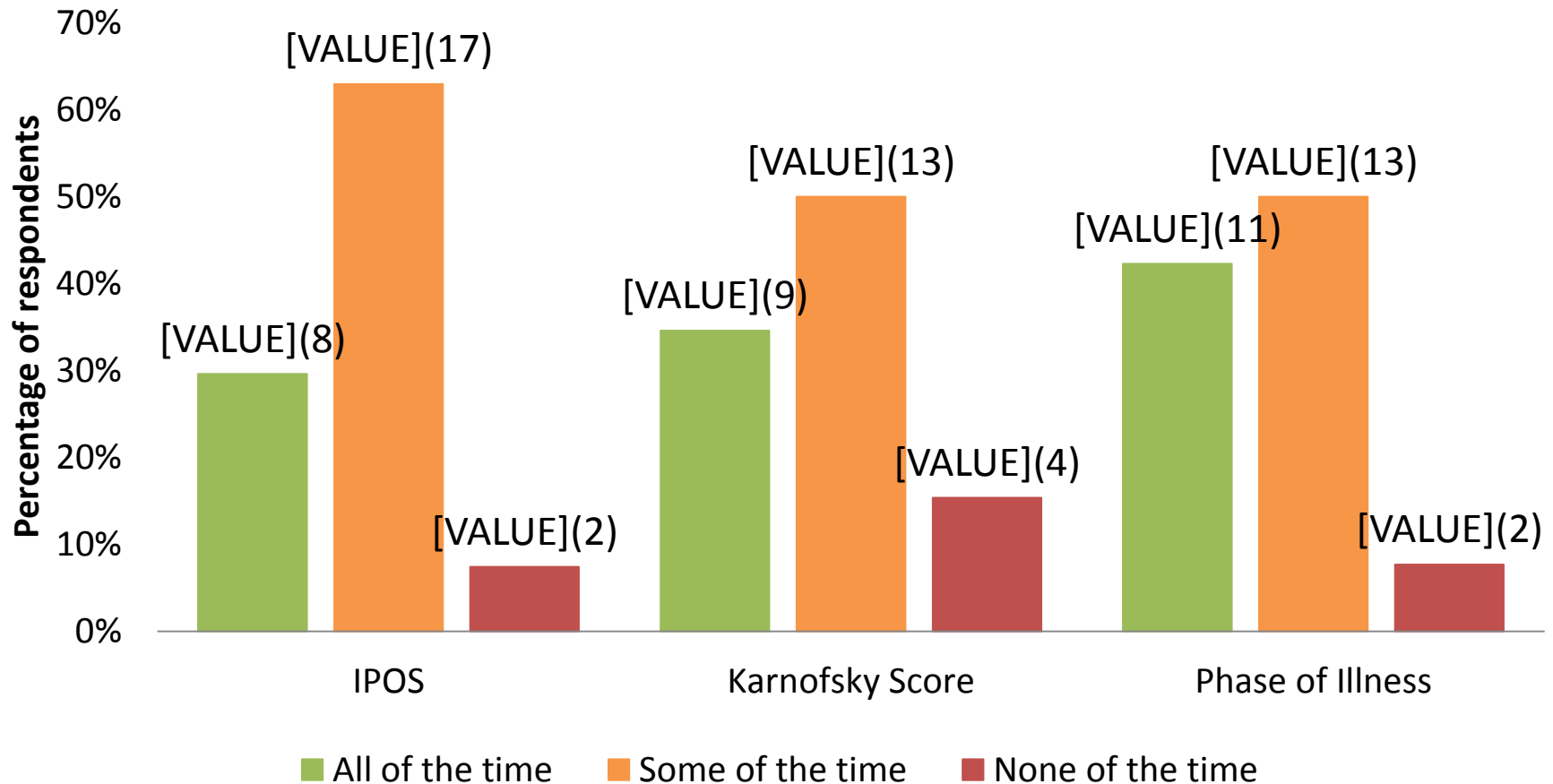


Methods

- All **clinical staff** who use the OACC measures were invited to take part
- **Online questionnaire** sent by email: 30th September 2020
- **Paper**-based questionnaires offered at MDT
- **Reminders**: Emails, in meetings, and posters around the building
- Collection by Scholl Academic Centre (SAC) Academic **Research Team**
- Data collection **closed**: 28th October 2020
- Data **analysis**: Summary statistics and thematic analysis

Use of OACC measures

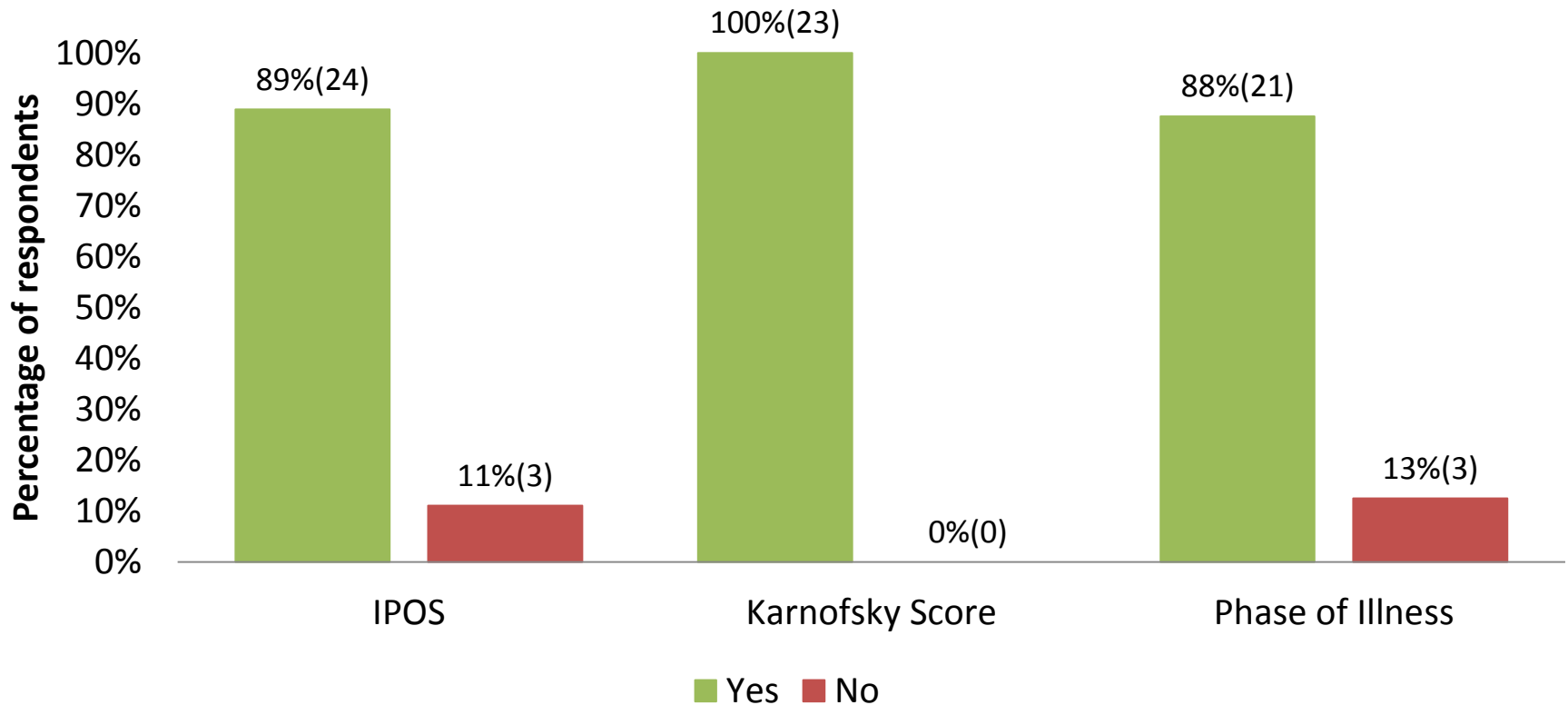
How often do you use...?



Missing responses excluded, N=27 IPOS, 26 Karnofsky, 26 Phase of illness

Confidence in using the OACC measures

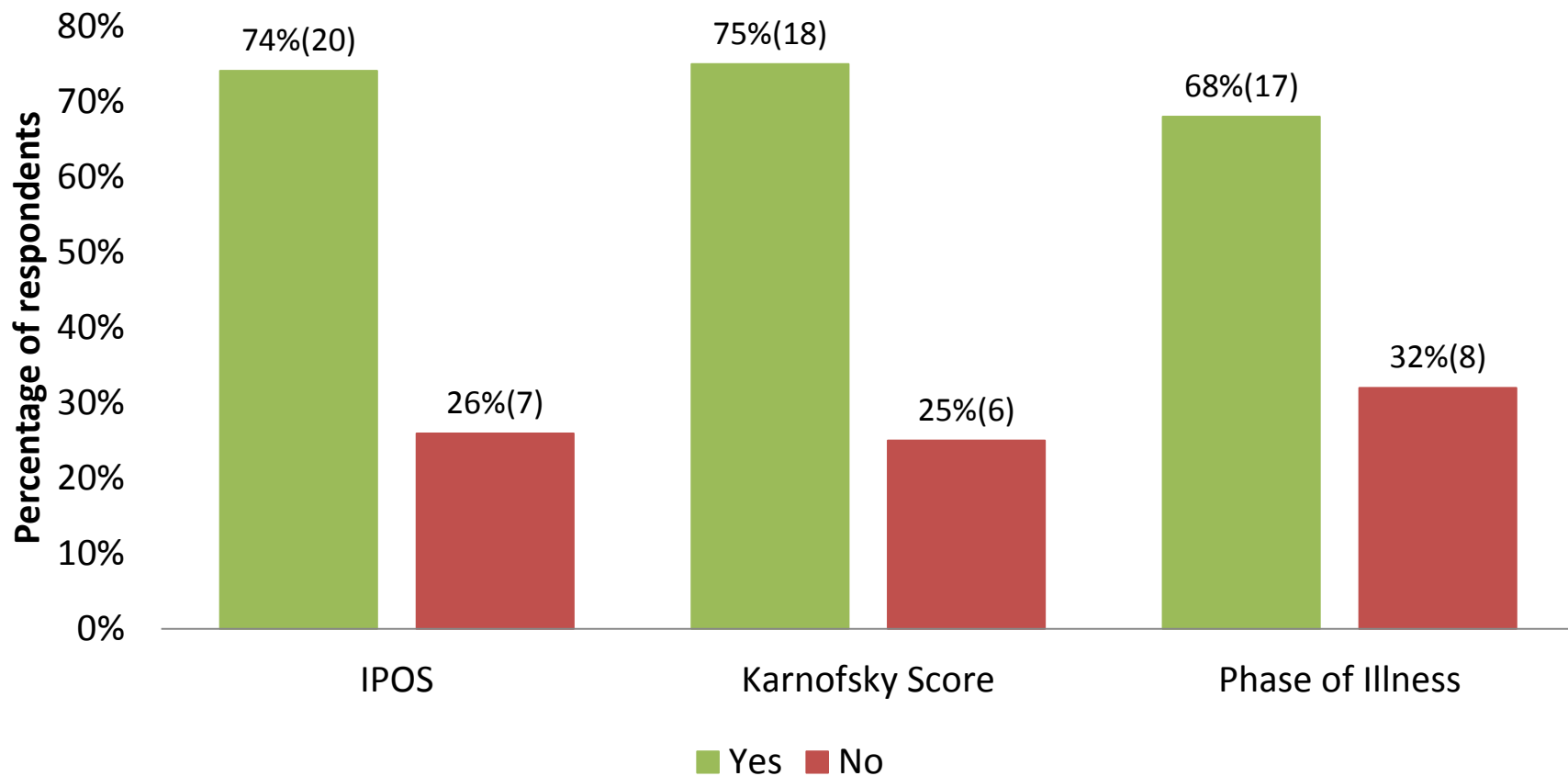
Are you confident that you are using the measure appropriately?



Missing responses excluded, N=27 IPOS, 23 Karnofsky, 24 Phase of illness

Assistance in clinical care

Do you feel that the measure assists in your clinical care?



Missing responses excluded, N=27 IPOS, 24 Karnofsky, 25 Phase of illness

What is working well

Assessment and monitoring

“I think it is a very valuable and useful tool that assists me in providing appropriate care and increasing service as required”

“You are able to prioritise the problem of patients, problems the need more attention, care plans updated”

Assists when planning
care

Help identify wider needs

“It is a system that everyone uses and understands and gives an overview of the patient which helps at MDT – as opposed to different systems/assessments within different departments”



Common framework among clinicians

What is not working well



Physical focus

“Not always appropriate as tends to focus on the physical”

Perceived lack of benefit

“I always assess my patients holistically, I don’t need a scoring system to tell me how ill they are”



Subjective

“Sometimes difficult to decide between % scores e.g. 60% or 70%, dependent on what you hear/observe in 1 hour assessment”

Specific issues

IPOS

- The 'at peace' question is difficult to answer
- The overall scoring method can miss patients

Karnofsky score

- Difficult to differentiate between percentage scores

Phase of Illness

- Lack of differentiation between 'unstable' and 'deteriorating'
- Sensitive to small changes in a patient's condition



How staff can be supported

Recommendations for use

- Add a 'not appropriate' option for questions/measure
- Data link between measures completed by patients and measures completed by staff

Improve use of OACC measures as outcome measures

- Standardise the use in practice – e.g. when used
- Report the results to clinical teams to demonstrate impact of care

Incorporate OACC in patient discussions – MDT and patient handovers

Other outcome measures which are more relevant to other services

More information and training

- How to complete measures following patient death/if staff not familiar with patient
- How often
- How to apply in MDT
- How to differentiate Phase of Illness phases
- Refresher session



Key messages

- **Widely used** and **positively perceived**
- **Similar** perceptions and use across the three outcome measures, however **specific issues** were identified
- Benefits in the **context of the direct care**
 - e.g. a tool for patient assessment
- Benefits as **outcome measures** were not evident - practitioners are not considering the **wider uses** of the OACC measures
 - e.g. caseload management, workforce planning, assessment of the impact of interventions, and effectiveness of the service



Is OACC the only option?

A case for ICECAP measures

- Palliative care is **holistic** and provided by a **multidisciplinary** team⁴
- The ICEpop CAPability (**ICECAP**) measures have a broader evaluative space and **multidimensional** nature⁷
- **Beyond health** outcomes: Also includes choice, relationships, dignity, support and preparation^{7,8}
- Supportive Care Measure (**ICECAP-SCM**) developed specifically for palliative and end of life care⁸
- Evidence shows that it is **acceptable** in a **hospice setting** and is easily **understood** by patients⁹



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Stay in touch, sign up to our newsletter at
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