

Person centred, value based: the new national programme for improving palliative and end of life care for all in Wales

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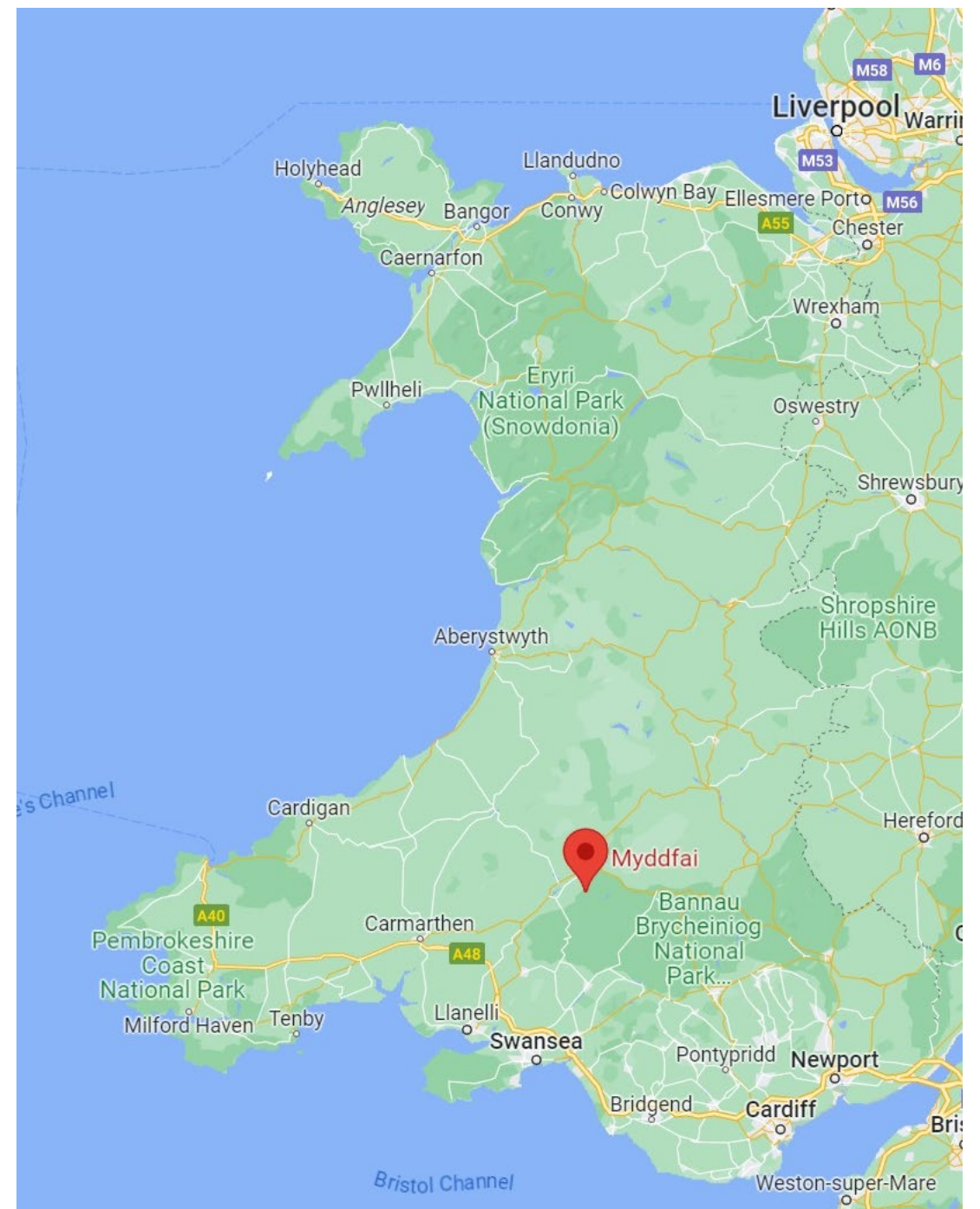
Hospice UK

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THE
PHYSICIANS
OF
MYDDFAI
TRANSLATED, WITH
AN INTRODUCTION, BY
JOHN PUGHE
ANCIENT HERBAL
AND OTHER REMEDIES
ASSOCIATED WITH A LEGEND
OF THE LADY OF THE LAKE
A FACSIMILE REPRINT







Context

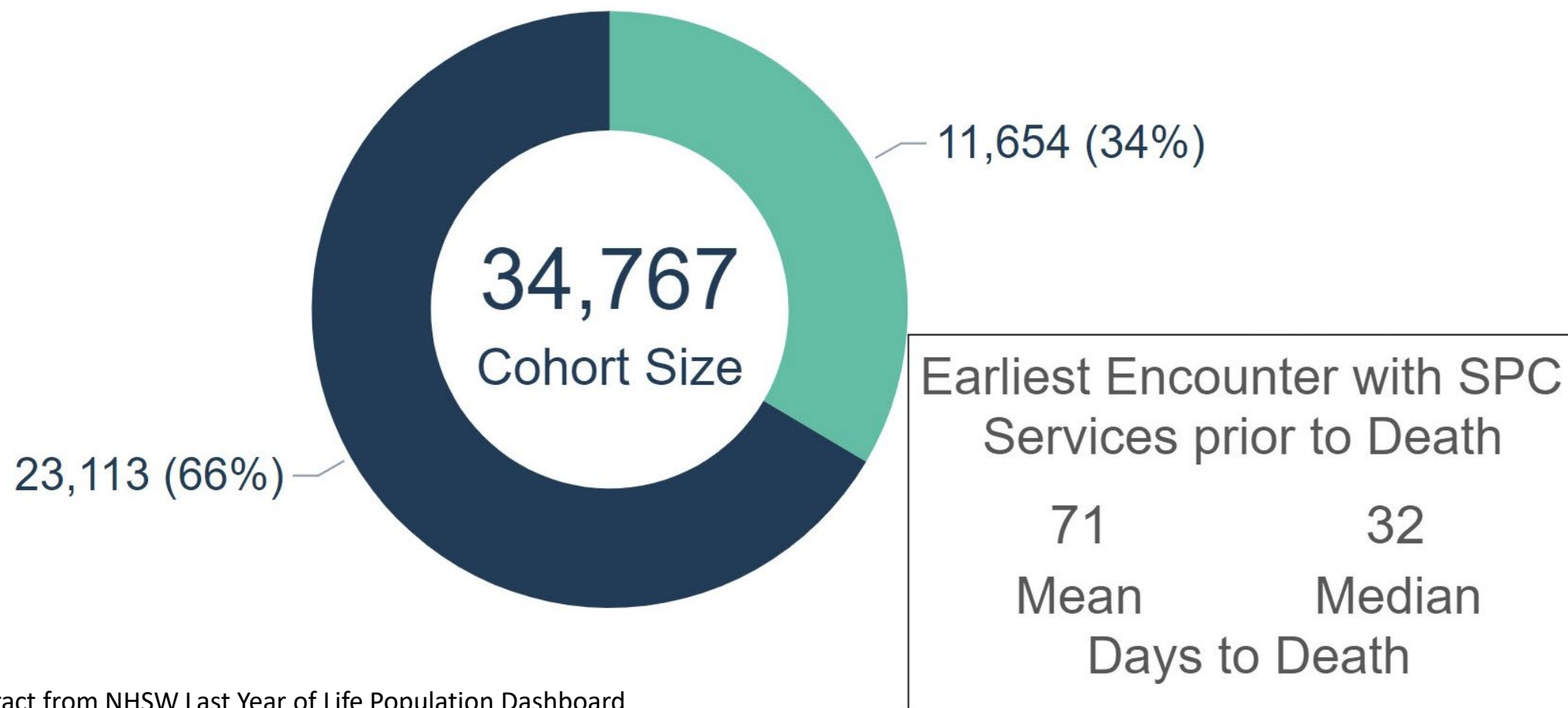
- Population overall older than UK, dispersed but locally dense, with higher rates of some serious illness and lower household incomes
- Health devolved to Wales since 1999
- Welsh Government + Senedd Cymru (Welsh Parliament)
- 7 integrated health boards provide/commission health care to resident population within the budget provided to them
- Growing digitisation + scope for data linkage
- Strong cross party support for recognition of PEOLC & hospices
- Variation in balance of voluntary hospices & NHS provision

Where have we got to?

- Strong multiprofessional specialist services across Wales for adults & children
- Equity in provision of some degree of 7/7 & 24/7 specialist support
- World class education, training, research-policy pipeline
- All Wales coverage for paediatric palliative care
- Close link between specialists & the non specialist workforce which does most of the adult palliative care
 - 66% of people with some PEOLC need are never referred to a specialist
 - The 34% are referred late
 - Even when there's specialist support much of their care is undertaken by non specialists

Patients by Specialist Palliative Care

● Received SPC ● No SPC



• Extract from NSW Last Year of Life Population Dashboard

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Where have we got to?

- But
 - Persisting inequity
 - Persisting concern about funding
 - Relative dearth of systematic measurement of experience
 - Near complete dearth of systematic measurement of outcomes
 - Uncertain timely identification
 - Uncertain track record on translating research into practice
 - Pretty much no idea what it all costs

What to do?

- What does 'thinking differently' mean in this context?
- How do we meet the unmet need plus the projected growth in numbers and complexity?
- How can we tackle questions of equity, quality, value?

“In God we trust; all others bring data.”

— **W. Edwards Deming**

What good do we do?

- Evidence from research
 - But however good the recipe, you have to follow it
- Evidence from audit & QI
 - But tends to focus on process not result
- Person centred value based health & care
 - Focuses on the outputs

What good do we do?

- What effect does our care have in reality on patients & families?
- Does it offer good value compared with other ways the resources could be used?
 - HV vs OPA vs day care...
 - Skill mix
 - Prioritisation
 - Proactive vs reactive

Value based health care

- ‘The equitable, sustainable and transparent use of the available resources to achieve better outcomes and experiences for every person.’

• CEBM, <https://www.cebm.ox.ac.uk/resources/reports/defining-value-based-healthcare-in-the-nhs#:~:text=Value%2Dbased%20healthcare%20is%20the,and%20experiences%20for%20every%20person.>

- So focus on doing more of what helps & less of what doesn't
 - focus on effects not (merely) on process & structure
- For person centred value based PEOLC, need to understand
 - the relationship between input & output
 - the relationship between effect & benefit
- Subjective preference carries much greater weight in PEOLC when attainable physiological goals are much more constrained

The programme

- Established & operating in the context of a new NHS executive structure delivering on these value-based principles
- Guided by Quality Statement for PEOLC published by government
- Broadest stakeholder engagement we can get
- Overseen by a board, informed by a number of professional & advisory groups
- Strong 3rd sector challenge
- Work programme informed partly by requests from government for advice on service specification, models, funding & partly by priorities identified in practice

The programme

- Patient experience
 - New system-wide process for feedback
 - Bespoke PEOLC questions
 - Implementation ongoing
- Outcomes
 - Patient-reported, proxy-reported, clinical
 - Adult core outcome set defined + suite of tools chosen
 - Pilots starting
- Advice
 - Ongoing role in advising government, other programmes, & providers

The programme

- Questions

- How do we centre the user perspective?
- What's the right model across the whole system?
- What does the future hold?
- What's the right balance between specialist & non-specialist PC?
- What are the unintended consequences of a value-based approach?
- How do we make sure we capture everything adding value?
- What variation is warranted & what is unwarranted?
- How do we support hospices both to contribute as part of an integrated system and to fulfil their distinct role?

Age – just a number?

- Programme is all age
- Specific considerations for children & young people
 - Children's hospices
 - Specialist multiprofessional teams at health board or regional level
 - 24/7 national on call rota
- Challenges
 - Variation
 - Long & unpredictable duration
 - Marked socioeconomic challenges & financial pressures on families

Workforce

- What's the right workforce model?
 - What professional mix do we need?
 - Why can't we recruit & what can we do about it?
 - What's the relationship between need & profession?
 - How do we get workforce right across statutory & voluntary sectors?
 - How can we best support the wider non-specialist palliative care workforce?
 - Is there a single right model?
- Broadly trying to broaden skill mix rather than putting all eggs in one basket

Where next?

- Service specification - more 'what?', maybe some 'how?'
- Emphasis on value
- Emphasis on equity
- Across statutory & voluntary sectors
- Across the whole spectrum of complexity & specialisation
- What are we doing that isn't working, & what aren't we doing that would?

Opportunity

- Contribute to understanding of value
- Contribute to future projections
- Contribute to the evidence
- Apply it
- Challenge

Why?

‘for the ayde and comfort of the poore sikke, blynde, aged and impotent persones, beyng not able to helpe themselffs, nor hauyning any place certeyn whereyn they may be lodged, cherysshed and refressed tyll they be cured and holpen of theyre dyseases and syckesse.’

Lord Mayor & citizens of London, petitioning Henry VIII to refound the priories of St Bartholomew & St Thomas

Cited by Cicely Saunders in the foreword to the Oxford Textbook of Palliative Medicine