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focus on dementia

Overview of the HIS National Work on Dementia

Cesar Rodriguez
Old Age Psychiatrist, AMD Older People, NHS Tayside
FoD National Advisor (Psychiatry), ihub, HIS

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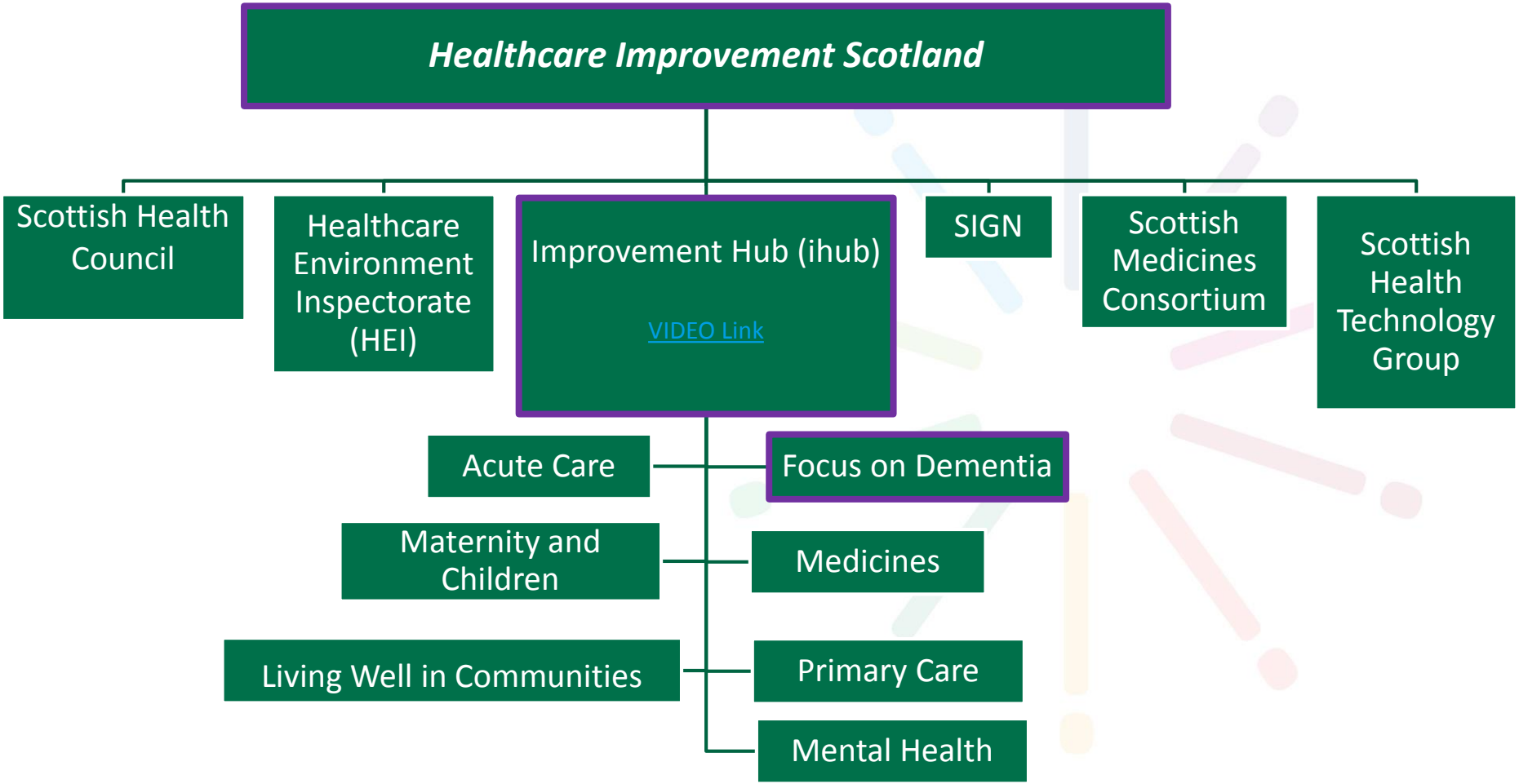
The Improvement Hub (ihub) is a part of Healthcare Improvement Scotland

Introduction

1. **Focus on Dementia: background and portfolio**
2. **Working on an ethical and legal framework**
3. **Secondment in HIS: my experience so far**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Acute Care
Focus on Dementia
Maternity and Children
Medicines
Living Well in Communities
Primary Care
Mental Health

Focus on Dementia

National improvement portfolio established by the Scottish Government, working in partnership with national organisations, HSCPs, people with dementia and carers to reduce variation and improve quality of care.

Taking a whole pathway approach, our work support:

1. improvements in diagnosis and post-diagnostic support
2. integrated care co-ordination in the community
3. specialist dementia units
4. acute care and advanced care

All of this work is supporting the implementation of Scotland's dementia strategies and informing future policy and practice.

Improving quality and experience of care and support for people with dementia, staff and carers from diagnosis to end of life and across a range of settings

Aim: To Improve the quality and experience of care and support for people with dementia, staff and carers (supporting commitments 1-7 of Scotland's dementia strategy) by March 2020

Scotland's Dementia Strategy Outcomes

Diagnosis and Post Diagnostic Support

Demographics

COMMITMENT 1: We will revise the national post-diagnostic dementia service offer to enhance its focus on personalisation and personal outcomes in the delivery of post-diagnostic services.

- Since 2014, over 6,000 people in Scotland with dementia each year have received post diagnostic support with an identified post diagnostic support practitioner.
- Of those people referred for dementia post diagnostic support over 60% of people receive this within 3 months of their diagnosis.
- Scotland remains the only country in the world to have a guarantee that anyone being newly diagnosed as having dementia has a minimum of one year post diagnostic support with an identified named worker. Every Board area in Scotland reports on their performance as part of their Local Delivery Plan Target.
- By 2020 the no. people diagnosed be 19,473/year a 17% increase from 2014 (16,712)

Diagnosis and Post Diagnostic Support

Workstreams

COMMITMENT 1: We will revise the national post-diagnostic dementia service offer to enhance its focus on personalisation and personal outcomes in the delivery of post-diagnostic services.

1. A Quality Improvement Framework for PDS
2. Testing the value of PDS in Primary Care
3. Network to share and connect practice

Shaped by personal outcomes

- I am confident in the people who support me following my diagnosis
- I experience high quality post-diagnostic support at the right time and at the right level for me
- I know more about my dementia and have adjusted to my diagnosis
- I feel listened to and what matters to me is at the heart of decisions about me
- I feel better about the future knowing I have made plans.

Diagnosis and Post Diagnostic Support

Workstreams

COMMITMENT 2: We will test and independently evaluate the relocation of post-diagnostic dementia services in primary care hubs as part of the modernisation of primary care

- Three test sites (GP clusters)
  1. North East Edinburgh: 8 Practices, 57,724 (740)
  2. Nithsdale (Dumfries and Galloway): 9 Practices, 59,217 (593)
  3. Shetland: all 10 Practices, 23,000 (170)

- The hypothesis is that relocation of post- diagnostic support to primary care will help improve access, timely diagnosis, improve coordination of care, increase practitioner confidence and improve outcomes for people with dementia and their carers

Integrated Care Co-ordination

COMMITMENT 3: We will support the Integration Authorities to improve services and support for people with dementia as part of our implementation of key actions on delayed discharge, reducing unscheduled bed days, improving palliative and end–of-life care and strengthening community care.

COMMITMENT 4: We will consider the learning from the independent evaluation of the 8 Pillars project on the benefits and challenges of providing home-based care coordination and proactive, therapeutic integrated home care for people with dementia.

Initial work needed on different ihub portfolios:

- Proposal for whole system improvement work
- Ihub event to share and connect practice (Feb 2018)

The age group most likely to be given a diagnosis 80-84 therefore likely to have comorbid conditions

Advanced Care

Demographics and key messages

COMMITMENT 5: We will test and evaluate Alzheimer Scotland's Advanced Care Dementia Palliative and End of Life Care Model

COMMITMENT 6: We will work with stakeholders to identify ways to make improvements in PEOLC for people with dementia

- 1 in 3 people over 65 may die with dementia
- AD/Dementia accounting for around 10% of all deaths
- 2 in every 5 people with dementia die in hospital
- ¾ of people with dementia had at least 1 ED attendance in their last year of life, 44.5% on the last month, 26% stay a period in excess of 3 months
- People with dementia who received palliative care typically did not begin receiving it until 2 weeks before death
- Palliative care and dementia care mostly not joined up
- Identification of advanced stage/palliative care needs still poorly recognised

Advanced Care

Workstreams

COMMITMENT 5: We will test and evaluate Alzheimer Scotland's Advanced Care Dementia Palliative and End of Life Care Model

COMMITMENT 6: We will work with stakeholders to identify ways to make improvements in PEOLC for people with dementia

- FoD is joining Living Well in Communities who leads on PEOLC following the SG's "Strategic Framework on PEOLC 2016-2021"
- There are 6 HSCPs sites concentrating on different aspects.
- FoD will support not only Dundee HSCP but those other sites (possibly Glasgow and P&K with people with dementia in other settings)

COMMITMENT 7: We will continue to implement national action plans to improve services for people with dementia in **acute care** and specialist NHS care, strengthening links with activity on delayed discharge, avoidable admissions and inappropriately long stays in hospital.

Acute Care

Demographics

- People with dementia are more likely to be admitted to hospital than people without dementia
- People with dementia over the age of 65 occupy an estimated 25% of acute beds.
- Only 1/3 have a previous diagnosis
- 6% people with dementia inpatients at any one time
- People who died in acute less likely to be referred to palliative care and less likely to be prescribed palliative medicines

Acute Care

Workstream

COMMITMENT 7: We will continue to implement national action plans to improve services for people with dementia in **acute care** and specialist NHS care, strengthening links with activity on delayed discharge, avoidable admissions and inappropriately long stays in hospital.

- FoD carried out critical success factors analysis in Aberdeen Royal Infirmary Department of Medicine for the Elderly which identified improvements in the care of people with dementia in acute settings. http://ihub.scot/media/2298/20170523-fod-grampian-report-1-0-web.pdf
- Good infrastructure to build on through Alzheimer Scotland/AHP consultant and dementia champions network
- Awaiting funding for spreading and collaborative work between FoD and Acute Care portfolios.

Specialist Dementia Units

Improvement Programme

COMMITMENT 7: We will continue to implement national action plans to improve services for people with dementia in acute care and **specialist NHS care**, strengthening links with activity on delayed discharge, avoidable admissions and inappropriately long stays in hospital.

- Background to the commission of this work in 2016:
  - 2nd Dementia Strategy: commitment 11 (QESDC)
  - MWC's "Dignity and Respect dementia continuing care visits" 2014

- 4 demonstrator sites:
  - Balmore Ward, Leverndale Hospital, NHS GG&C
  - Project Bank, Findlay House, Edinburgh, NHS Lothian
  - Strathbeg Ward, Royal Cornhill Hospital, Aberdeen, NHS Grampian
  - Orbiston Unit, Hatton Lea Care Home, Bellshill, Lanarkshire

- Use of improvement methodology and test of EBCD for this programme. Potential development of a yammer group for psychiatrists around this.

- Development of an ethical and legal framework

SDUIP: Ethical and legal issues

Background:

- The use of EBCD in terms of interviews and observations (and the use of improvement methodology in general) for people who lacked capacity raised ethical and legal issues that needed consideration.
- My role within the team and interest in the subject led to collaborative work between FoD, NES and MWC to test guidelines with the demonstrator sites. To finalise and share with others.

Aims:

- To provide clarity about the ethical and legal issues that need to be considered when conducting recorded interviews and observations in Specialist Dementia Units using the EBCD process.
- To explore and understand the concept of **"Secondary purpose"** in the EBCD process vs 'care/treatment' as usual.
- Apply AWIA principles and awareness of Section 51.

Issues to consider

Maximising the meaningful involvement of people with dementia and carers in the EBCD interview and observation process with due regard to:

- **Always respecting people's human rights** – e.g. respect for privacy and dignity, and avoidance of harm. And very importantly with the right to participate in decisions regarding care received (**Health and Social Care Standards**)
- Consent and capacity to consent issues
- Ethics and legality –correct application of legislation and compliance with national and local guidelines.
- Compliance with our Codes of Professional Conduct
- Considering what are the benefits to the person
- The information, support and training needs of interviewers and interviewees involved in the EBCD process

Ethical principles applied to QI

- Favourable benefit/risk balance
- Scientifically valid
- Equitable and reflecting priorities
- Value
- Awareness of conflict of obligations to patients

If the person lacks capacity to consent to participate

1. Is necessary, and benefits the patient or is in their best interest
2. That the purpose cannot be achieved in a way that is less restrictive of the patient's rights and choices.
3. To ascertain, if at all possible, their current and past wishes and preferences in this respect.
4. Where another person has legal authority to decide on the patient's behalf (Welfare Attorneys or Guardians), they must apply the same principles before giving or refusing consent for secondary purposes.
5. The adult is encouraged to use existing skills or develop new ones during the process.

Secondment in HIS

- 2 sessions a week with HIS from September 2016 to March 2019 (following grilling interview!).
- My first day I had to learn and be tested about the organisation's remit and governance issues.
- The objectives and PDP of my secondment as clinical advisor were agreed within two weeks.
- Within 2 months I had an appraisal with HIS medical Director that was included in my annual appraisal (my appraiser real impressed!). All clinical leads gather at the Clinical Forum.
- Support around improvement methodology and other expertise in the team, and within other HIS departments (comms, data analysts, project management ...)
- I had to sharpen my organisational and IT skills .
- I've learnt to tweet.
- Brilliant team working with time spent in team building and effective relationship and communication.
- Fair amount of travel and meeting and learning from other areas/teams.

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Thank you

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