LANCASTER UNIVERSITY

Advance care planning in care homes for older people

Dr Katherine Froggatt

International Observatory for End of Life Care

Lancaster University

k.froggatt@lancaster.ac.uk

The Nuffield Foundation

counsel + care
for older people, their families and carers

UWE BRISTOL University of the West of England

International Observatory on End of Life Care

Outline

- Background
- Research Study
  - Aims
  - Methods
  - Key findings
- Issues for further consideration

Acknowledgements

- Funded by The Nuffield Foundation
- A partnership project between Counsel & Care, Lancaster University and the University of the West of England.

Project Team

Katherine Froggatt (Lancaster University)
Suzanne Vaughan (Lancaster University)
Caroline Bernard (Counsel and Care)
Deirdre Wild (University of the West of England)

International Observatory on End of Life Care

Care Homes

- Care homes (nursing)
- Care homes (personal care)

Cross boundaries with respect to:

- **Focus of care** (nursing and/or personal care)
- **Funding** (health, social care, personal, family)
- **Service providers** (private, not-for-profit and public sector)
- **Regulation** (social care led, health care provided)

Care Home Population

Changing profile of people entering care homes

- Multiple disease processes common (Bowman et al, 2004)
- 62% residents with dementia (Matthews & Dening 2002)
- Challenges concerning communication and knowing people's views
- Increasingly frail and dependent population

International Observatory on End of Life Care

Living and dying in care homes

Living

- 5% people, over 65 years old, live in care homes (del Bono et al 2007)
- 410 000 older people lived in a care home (OFT 2005)

Dying

- Approximately 20% of people, over 65 years old, die in care homes (Davies and Seymour 2002)
- On average over 50% residents will die within 2yrs of admission (Katz & Peace 2003; Hockley et al. 2004)

International Observatory on End of Life Care

Resources

Staffing

- Difficulties of retention & recruitment (Redfern et al 2002)
- Much care provided by untrained carers
- Increasing accounts of cultural challenges
- Difficulties in accessing education(Katz & Peace 2003, Hall et al 2002)

Varied relationships with wider health care provision

- Primary care
- Specialist palliative care

International Observatory on End of Life Care

UK Policy Background

- Current emphasis on expressing and respecting choice in policy & service provision.
- Implementation of the Mental Capacity Act (2005) in 2007.
  - Assumes competency unless proved otherwise
  - Addresses anticipated lack of competency to express views
  - Nomination of consultees
    - Lasting Power of Attorney
    - Independent Mental Capacity Advocates
  - Legislates for ACP through:
    - advanced decision to refuse treatment
    - statement of wishes and preferences

In summary:

- Complex setting with regard to:
  - population characteristics and needs
  - models of care provision
  - wider societal dynamics (social, legal, ethical, financial)

Irish Context

- Two main groups of services - public and private
  - Health board geriatric homes/hospitals
  - Health board welfare homes
  - Health board district/community hospitals
  - Voluntary geriatric homes/hospitals
  - Private nursing homes
- Approx 30,000 beds across the sector
- 18,883 registered private and voluntary nursing home beds in Ireland (end 2007)

- Approximately 40% > 65 yrs die in nursing homes and public long-stay care facilities in Ireland (O'Shea et al 2008)

O'Shea *et al* 2008 *End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland.* Dublin: Irish Hospice Foundation and National Council on Ageing and Older People

International Observatory on End of Life Care

Advance Care Planning

- **Process of discussion**
  - between an individual and their care providers
  - when there is anticipated deterioration of an individual's condition
  - Resulting in reduced and or lack of capacity to make decisions and/or ability to communicate wishes
- **Could include:**
  - concerns
  - values or personal goals for care
  - understanding about illness and prognosis,
  - types of care or treatment

Adapted from Henry and Seymour (2007) *Advance Care Planning: A Guide for Health & Social Care Staff.* London, Department of Health.

International Observatory on End of Life Care

Aims of the Study

To identify:

- how care home residents are consulted about general care issues
- the extent to which ACP is undertaken
- which ACP ‘tools’ or processes in use
- level of staff training relevant to ACP
- managers' views about consultation and ACP
- elements of good practice in ACP in care homes (Good Practice Guide)

Methods

- Mixed methods descriptive study
- **Phase 1**: Postal questionnaire of 500 care home managers (42% response rate)
- **Phase 2**: Semi-structured interviews with 15 care home managers

International Observatory on End of Life Care

Findings

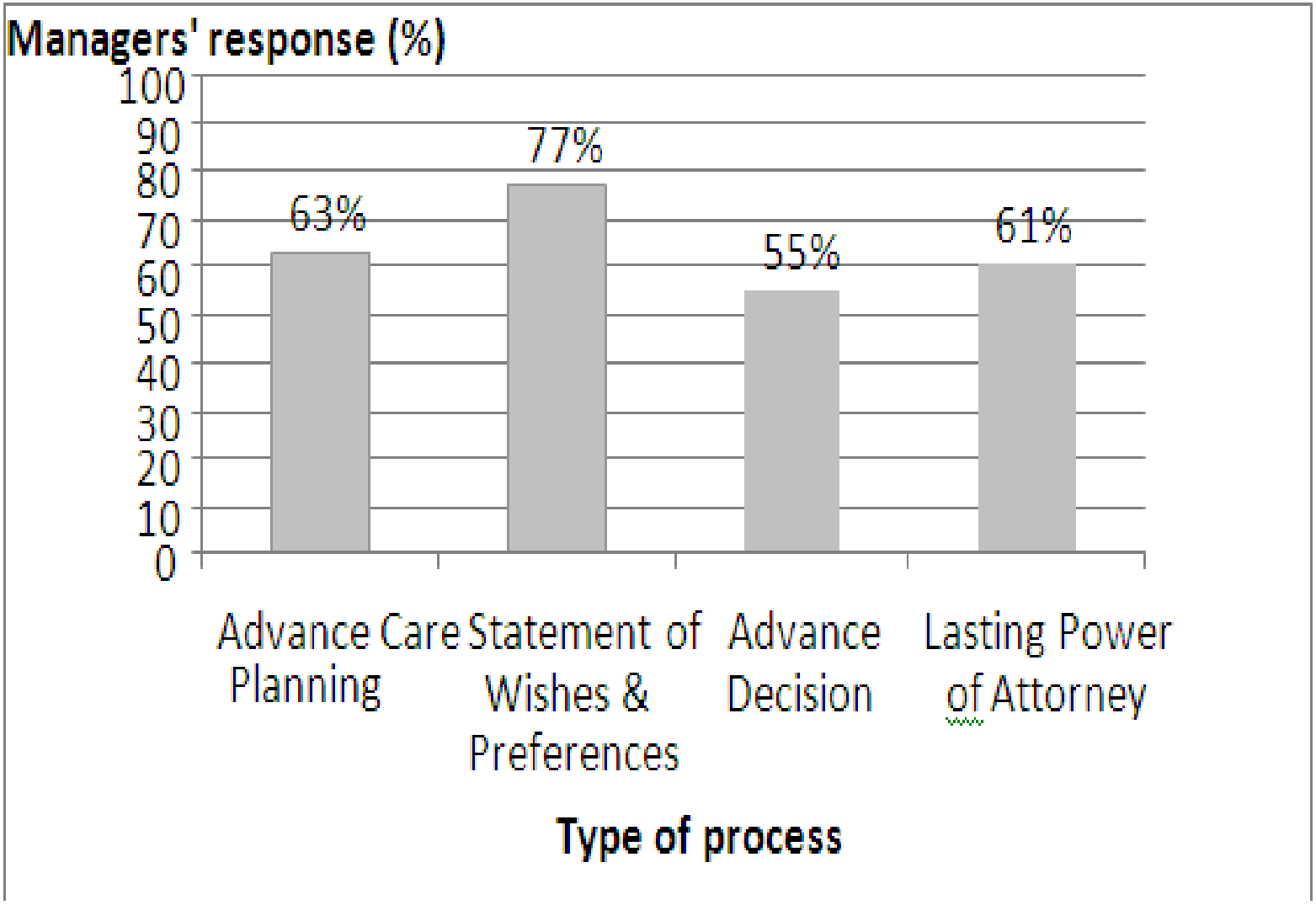
- Advance Care Planning
  - extent
  - processes adopted
- Factors influencing ACP use in care homes

International Observatory on End of Life Care

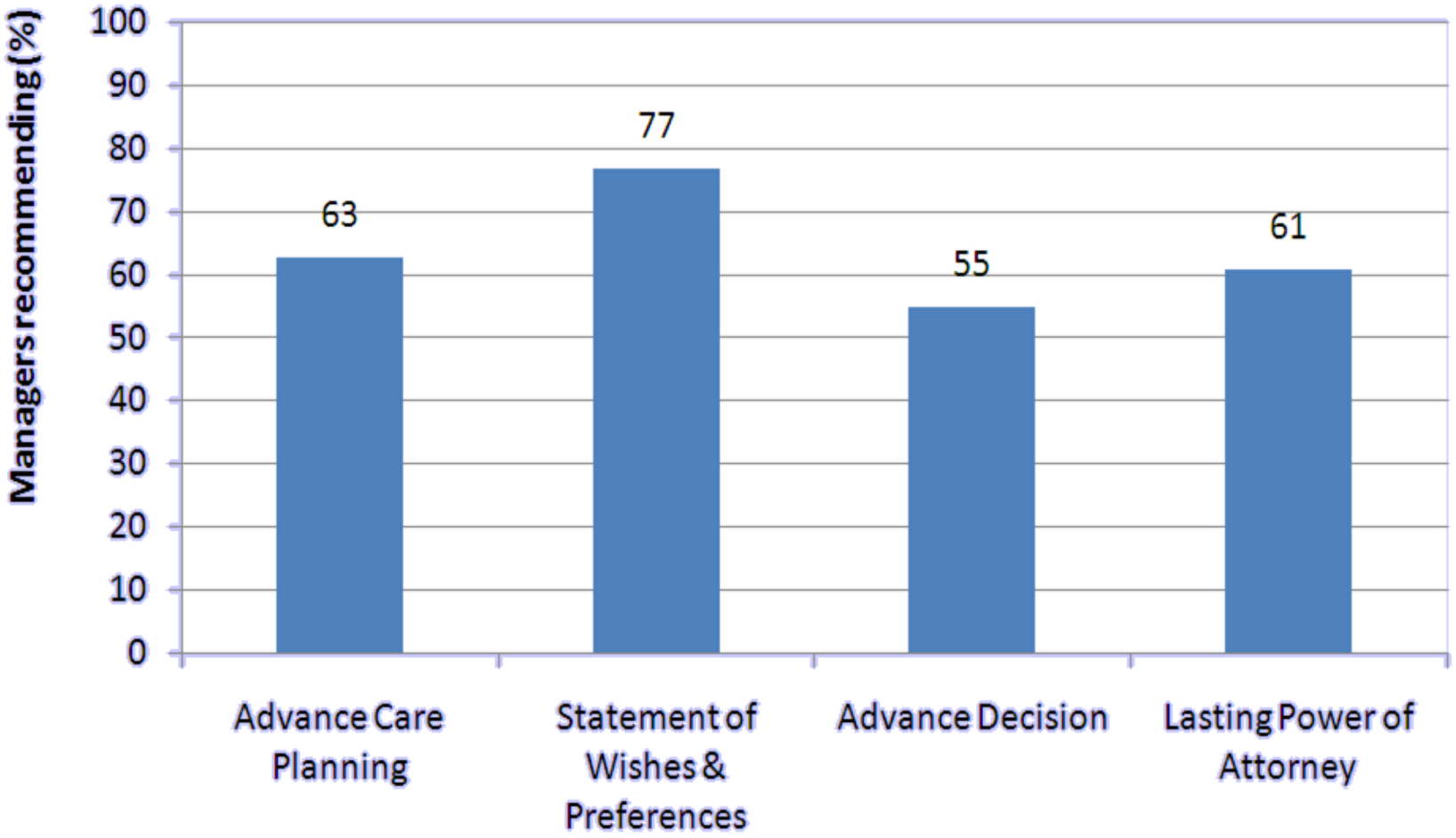
Perspectives on consultation

- Managers reported high levels of consultation practices with residents (>93%) and relatives (>95%) about general care issues
- 90% managers (n=189) recommended use of ACP within the care home.
- Varied by type of approach used

Type of process recommended

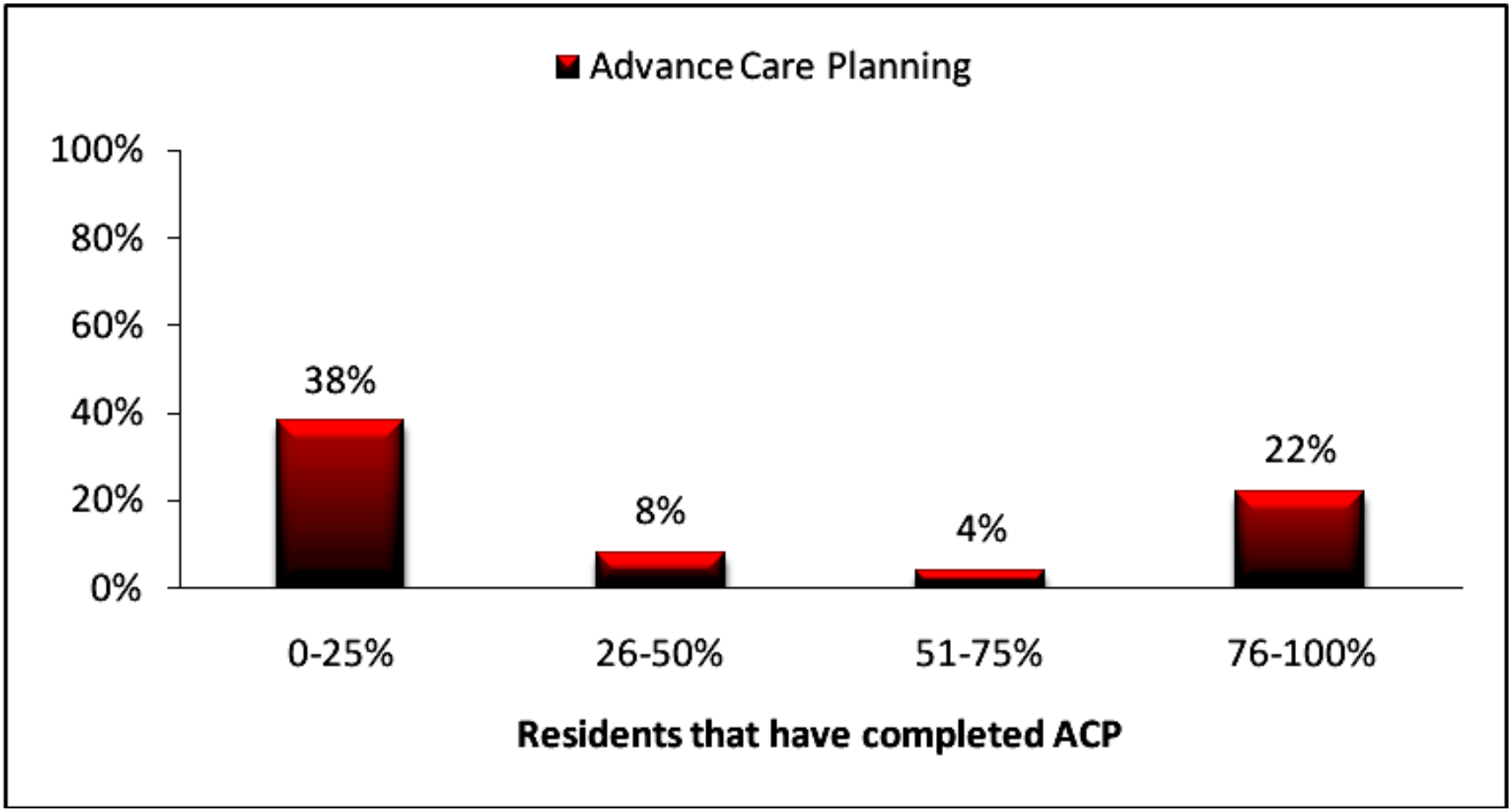


Type of process recommended by managers



International Observatory on End of Life Care

Residents completed ACP



International Observatory on End of Life Care

Use of End of Life Tools

- Three tools recommended by English End of Life Programme:
  - Liverpool Care Pathway,
  - Gold Standards Framework,
  - Preferred Priorities of Care
- 47% (n=101) managers reported use of one of the end of life tools
- LCP most frequently cited, by 34% managers (n=73).

International Observatory on End of Life Care

In summary:

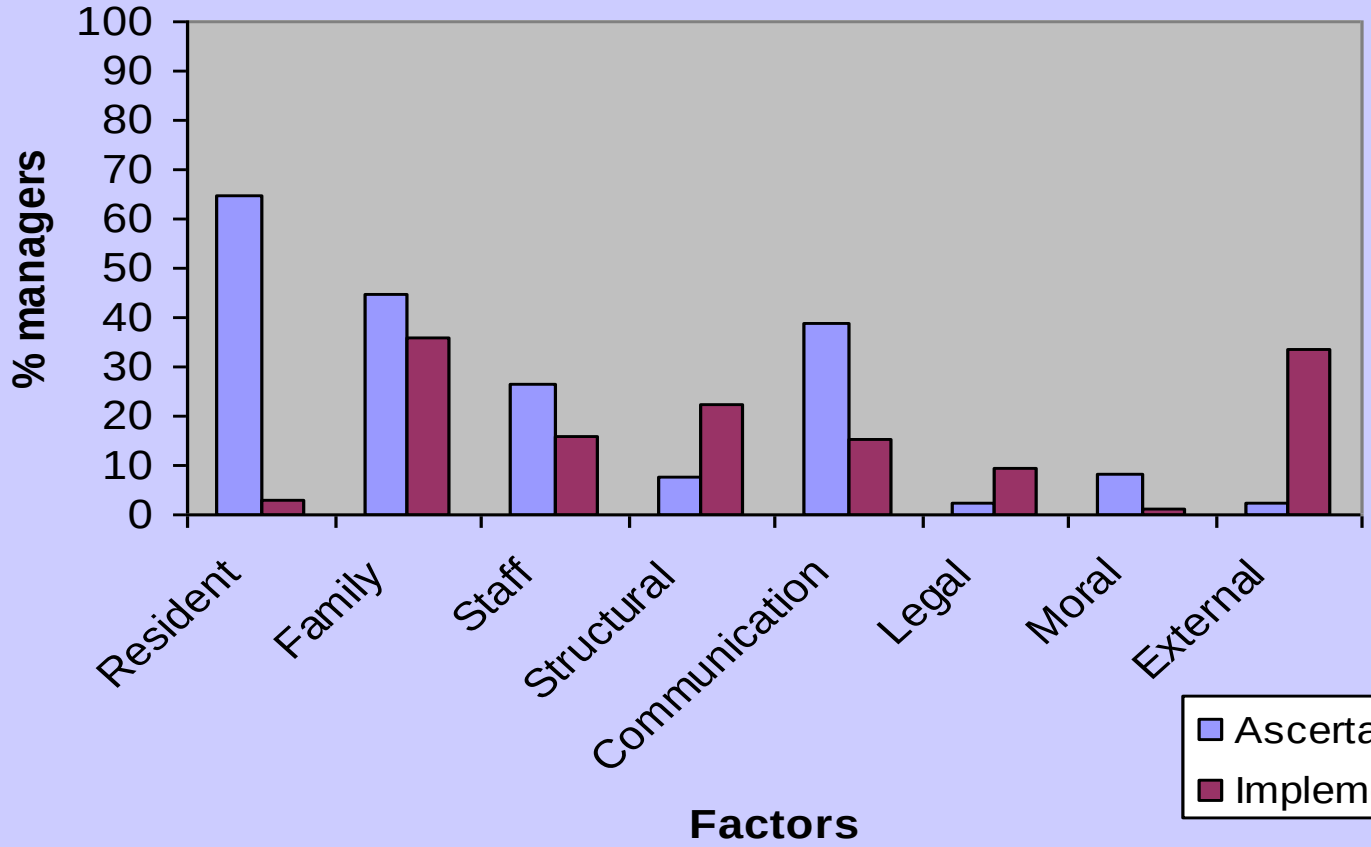
- Care home managers recognise importance of ACP
- Extent to which aspects of ACP being undertaken varies

International Observatory on End of Life Care

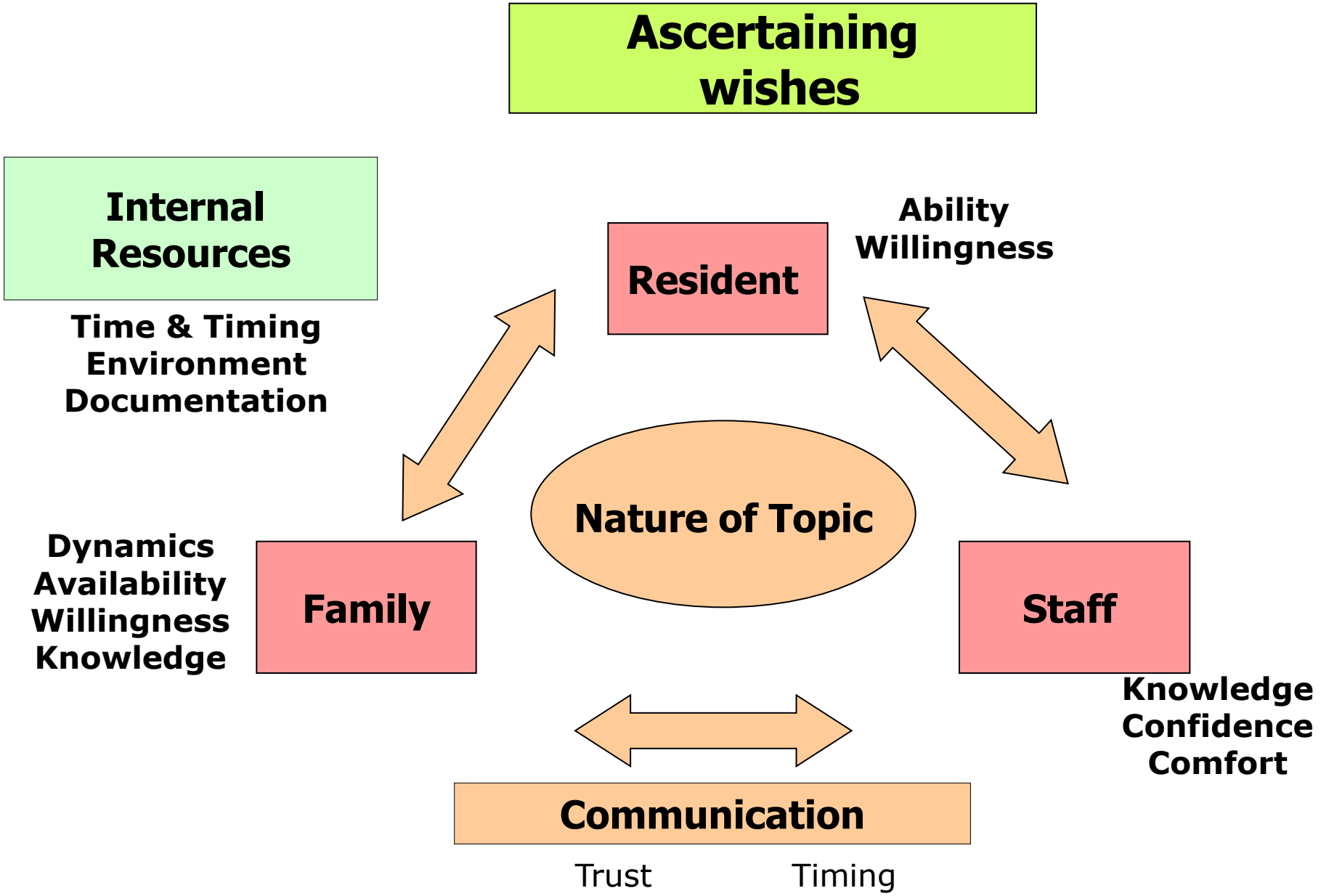
Understanding the context

- Ascertaining wishes
- Implementing wishes

Factors Influencing the Ascertaining and Implementation of ACP



International Observatory on End of Life Care


Ascertaining wishes
Internal Resources
Time & Timing
Environment
Documentation
Resident
Ability
Willingness
Nature of Topic
Dynamics
Availability
Willingness
Knowledge
Family
Staff
Knowledge
Confidence
Comfort
Communication
Trust
Timing

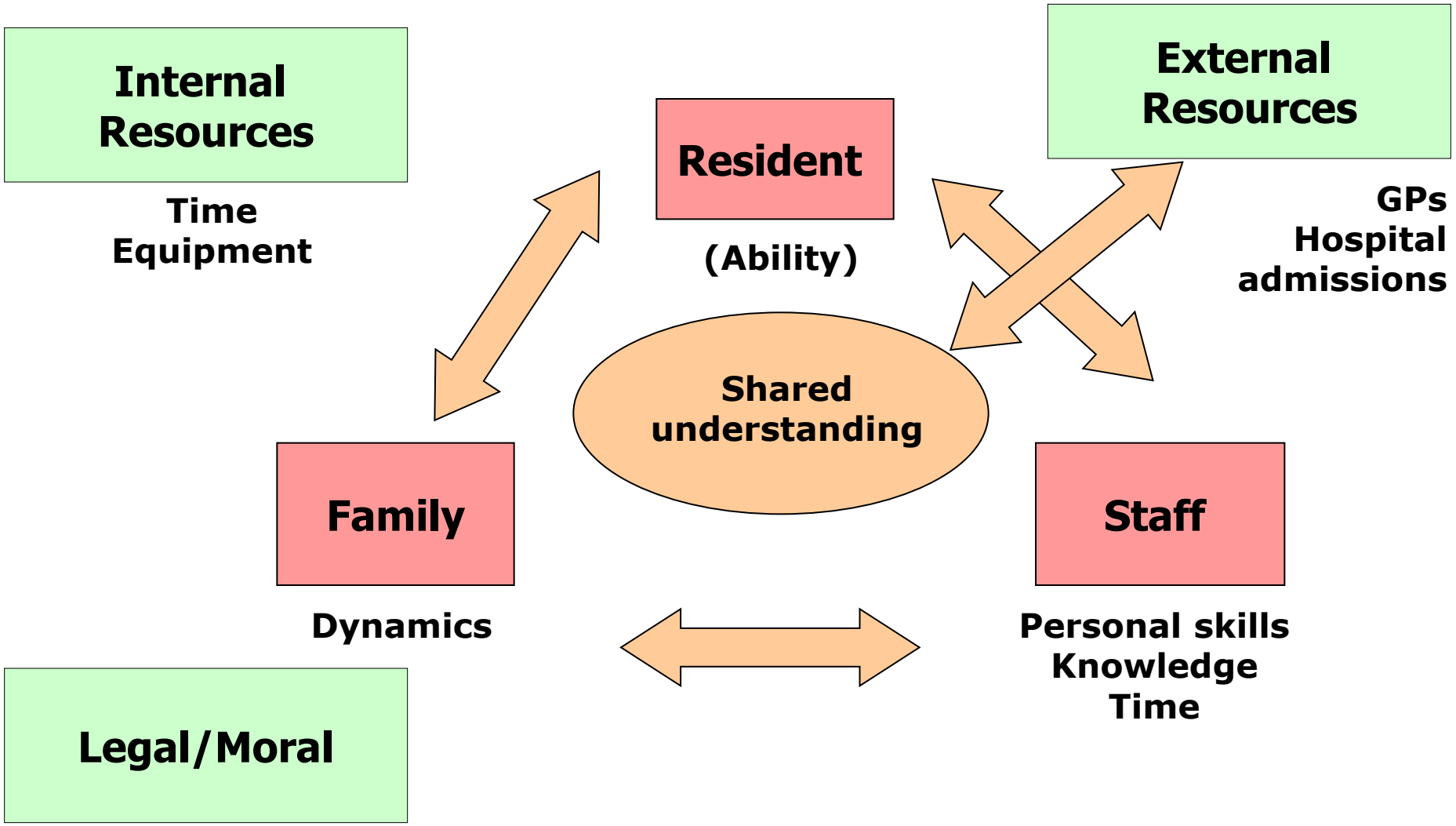
Resident ability

"We're not actually dementia registered, although we have got some that … are unable, a lot of them, to make that actual decision." (Manager 30)

Staff

"I think there's a lot of staff that do feel uncomfortable around issue of death. Some are frightened of the actual concept really and some are frightened of the families, of broaching the idea." (Manager 145)

Implementing Wishes



"I think the challenges that we've had, is not so much with relatives and residents; it's been more with the primary health care. And because what we found was it was very dependent on which surgery some of you belong to as the amount of support you get. You almost dread it when it is one surgery." (Manager 68)

Key Principles of ACP

- **Individually tailored**
  - Resident led
  - Issues addressed
  - How communication undertaken

- **Inclusive participation**
  - Family involvement
  - Different grades of staff
  - External staff (GPs, DNs)
  - Subject to resident agreement

- **Integrated processes**
  - With ongoing assessment of needs
  - Within current documentation

Good Practice Guide - Contents

- Place of ACP in care homes
- Legal context for ACP
- How to introduce ACP in your care home
- How an ACP can be written
- Who can help with this process
- What skills do staff need
- Where else to find help and information

International Observatory on End of Life Care

Issues for further consideration

- Who is responsible for what in ACP?
  - Ascertaining
  - Implementing
- Relationship between care home & wider service providers
- Information, training & support needs for all levels of staff
- Public education for the future care home population and their family member

Thank you for listening

Full report available from

www.eolc-observatory.net/policyevaluation/acp.htm

Good Practice Guide:

Butterworth C, Froggatt K and Vaughan S (2008) *Ascertaining Wishes: A Good Practice Guide.* London, Counsel and Care

£5.99, available from Counsel and Care (www.counselandcare.org.uk)

International Observatory on End of Life Care