



Connecting Health and social care to Offer Individualised Care at End of Life

## Development of a model of integrated working to promote person-centred end of life care at home

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Who am I?  
What is my  
interest?



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# What were the issues?

Global focus on people-centered and integrated care (WHO 2015)

Organisations are finding new ways of working together (National Palliative and End of Life Care Partnership (2016).

69% and 82% people with long-term conditions likely to have preceding palliative care needs (National End of Life Care Intelligence Network 2013)

UK policy commitment for person-centered practice and the need for effective collaboration (DH 2008; 2010; SG 2008; Welsh Government 2016).



# What were the issues?

Emphasis on improving patient experience, reducing length-of-stay in in-patient units made possible by effective integration (The Choice in End of Life Care Programme Board)

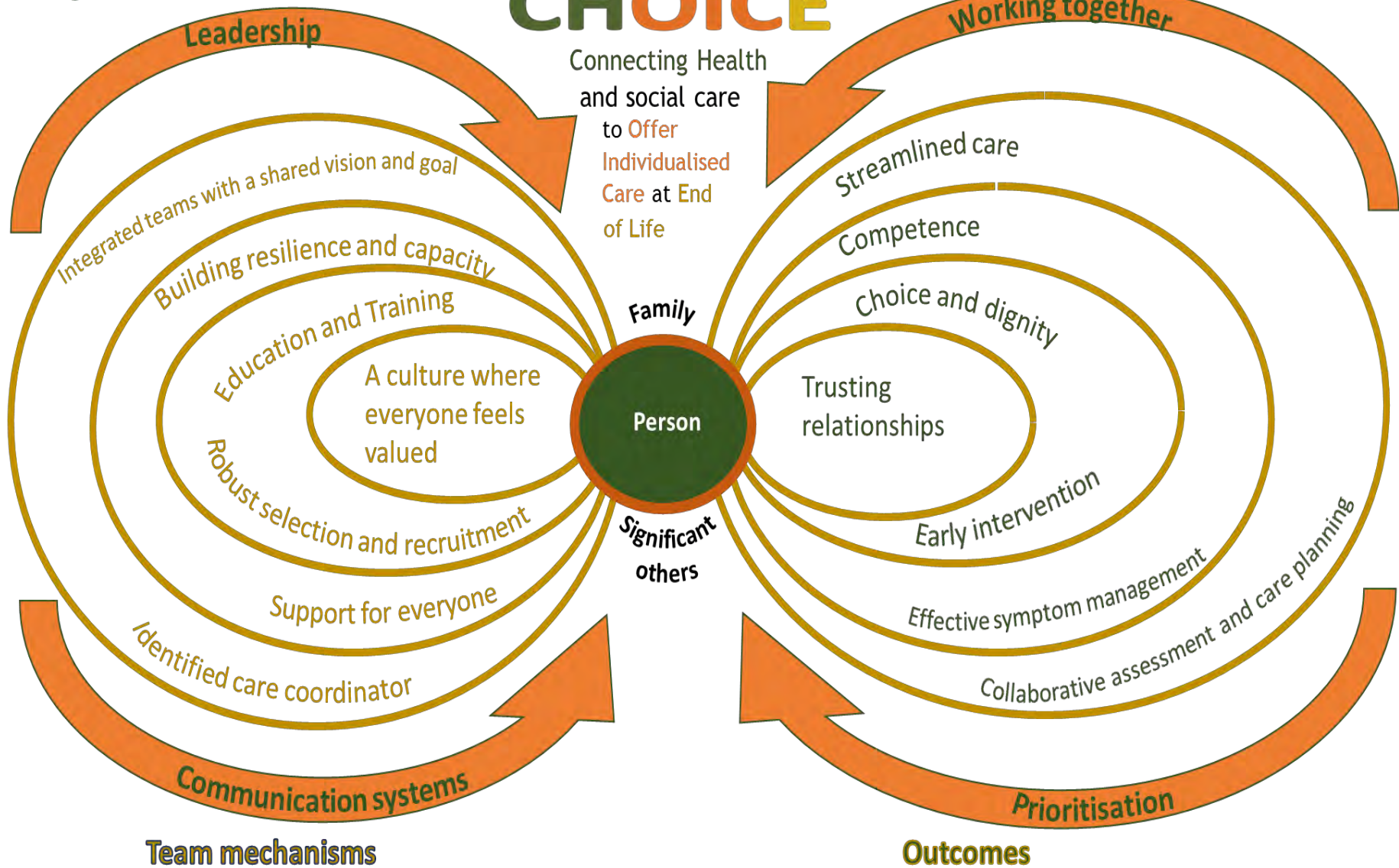
Care is fragmented with poor communication leading to social care workers in particular, feeling under supported and under-valued (Herber and Johnston 2013; Devlin and McIlpatrick 2009)



# Organisational structures

# CHOICE

# Outcomes



.....and some initial testing in practice



# What I'd like to share

- What approaches we took
- What methods we used
- What the findings were
- What next
- What was learnt



# What approaches we took

Person-centredness

*(McCormack & McCance 2006)*

Participatory research

*(McCormack & McCance (2006)*

Practice Development

*(McCormack et al. 2007)*

Realist synthesis

*(Pawson 2008)*



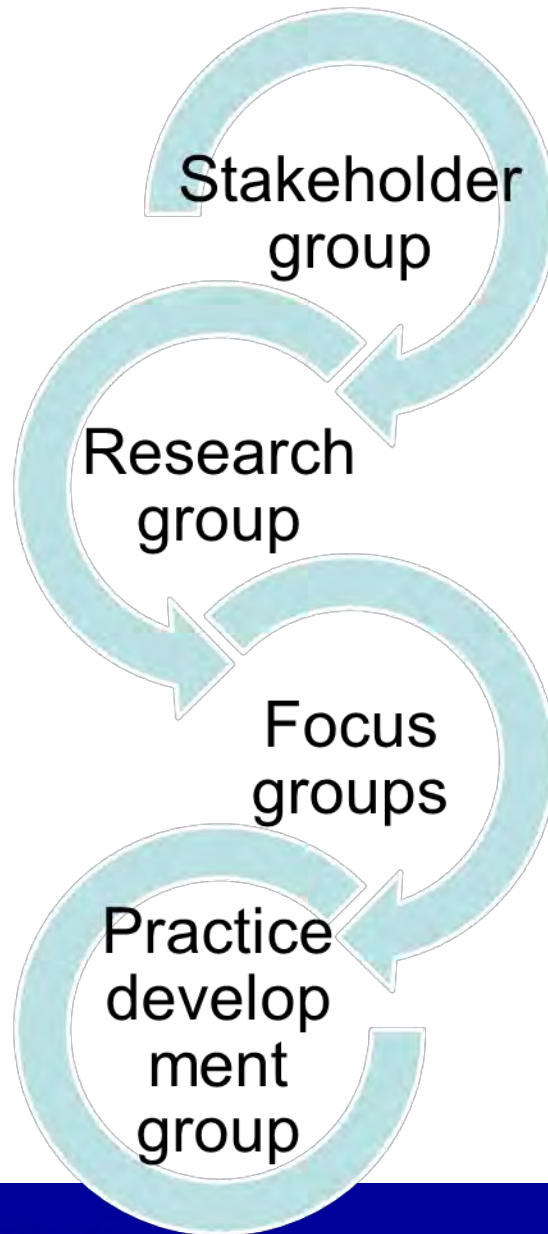


# Practice development approach

- Importance of values and visioning
- Participatory, collaborative and inclusive approaches to research and development
- Broad based approach to researching (in very practical ways) practice or work in health care
- Learning through the process

*(McCormack et al. 2007). Manley et al 2013).*





# How did we review the evidence?

- Realist synthesis (Pawson and Tilley 1997)
- Critical realism
- Drawn on a range of evidence
- $C + M = O$
- Generate hypothesis to test
- Systematic literature review
- Confirm or refute hypothesis



**outcome**

What we wanted to **mechanism**

*‘ In maintaining person-centred end of life care for patients and their families at home, what aspects of integration work, for whom do they work, in what circumstances and why?’*

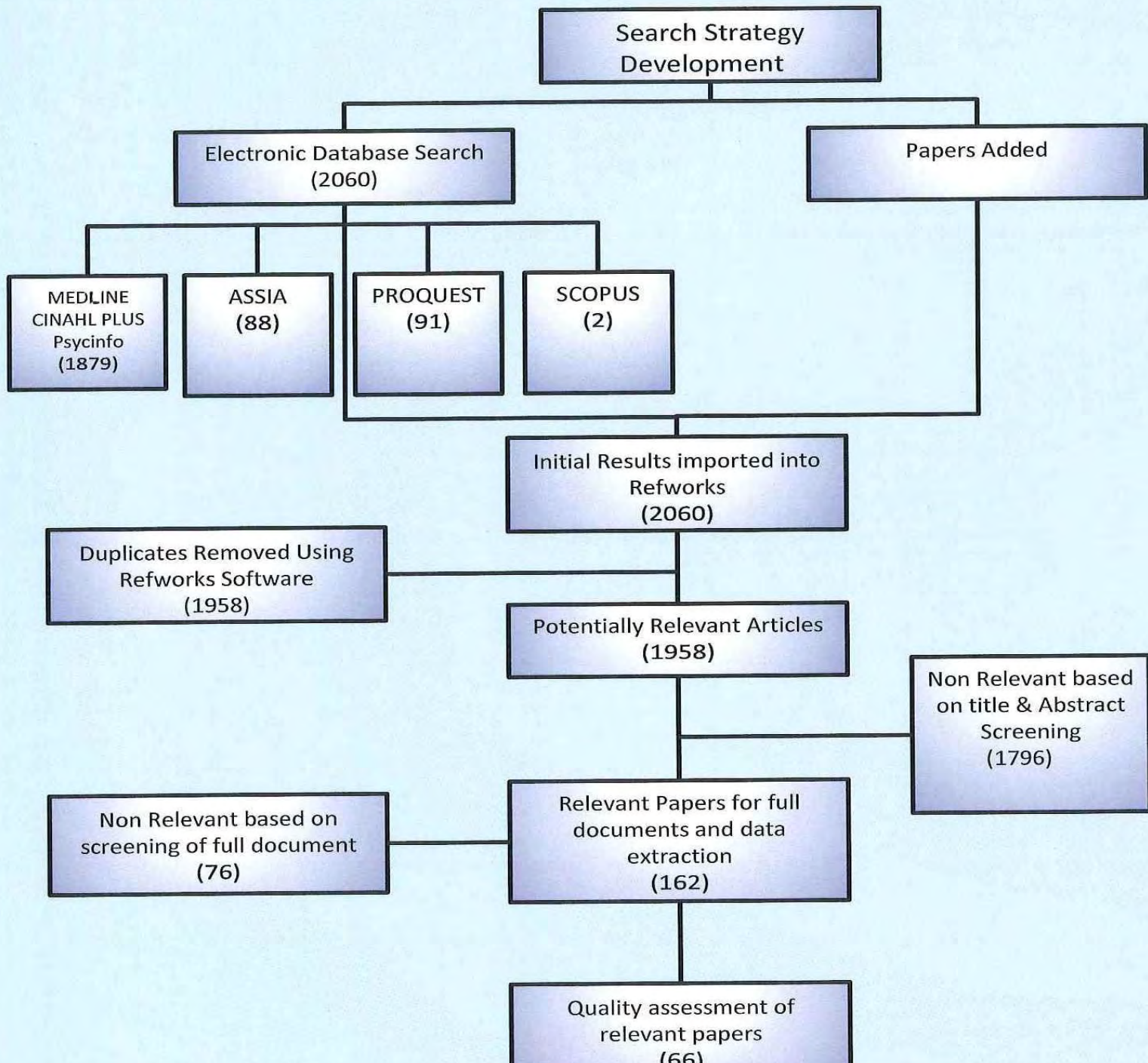
**context**



# What were our assumptions?

- A Person- centred approach drives integrated working for patients at end of life at home.
- Workplace and Organisational cultures affect successful integrated care at end of life.
- Working in partnership with patients and families will enable self-management and improve the patient and family experience of end of life care at home.
- Good case management features effective leadership supported by integrated organisational structures.
- A holistic person-centred model of end of life care will be enhanced by effective collaboration.





# What we found

## Mechanisms

- Establishing open, honest relationships
- Being responsive
- Providing holistic care
- Shared decision-making
- Team meetings
- Care coordination
- Using evidence-based guidelines

## Contextual factors

- Person-centred context
- Having adequate resources
- Seeing patients as partners in care
- Shared communication systems
- Role clarity
- Adequately prepared staff



# What we found

## Outcomes

- 'a good death'
- Person-centred care
- Streamlined care
- Meeting patient/carer expectation
- Quicker referral
- Staff confidence & competence
- Cost-effectiveness





# So....

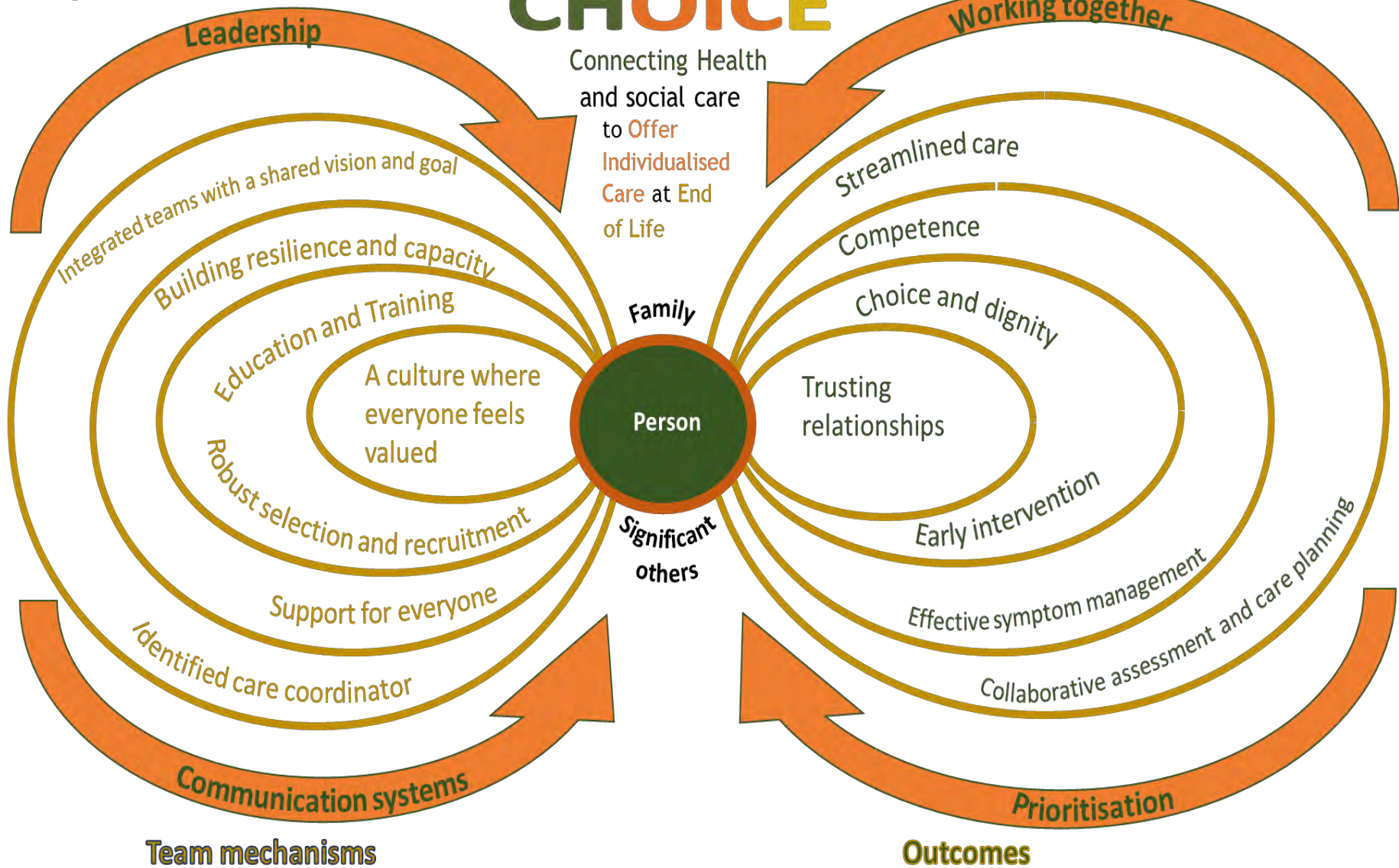
- What aspects of integrated caring at EoL provided at home work? - Evidence-based holistic care, provided through relationships built on trust, enabled by teams who communicate effectively and are able to be responsive
- For whom? – patients who wish to die at home, surrounded by those significant in their lives
- In what circumstances? – in an environment where person-centredness exists and patients and families are seen as partners in care; where there are shared communication systems between appropriately prepared staff with role clarity and adequate resources supporting this



# Organisational structures

# CHOICE

# Outcomes



# How we tested...

- Vision
- Prioritising
- Action planning
- Evaluation
- Refinement



*(McCormack et al. 2011; Manley et al. 2013)*



# What were the successes?

Personal acknowledgement of my own abilities.

Seeing individuals stepping out of their comfort zone such as writing for the local newsletter

Some barriers were broken down and new relationships formed.



# What were the challenges?

Not all the group participants managed to attend each session and this had an impact on the group dynamic

I felt some peoples expectations were unable to be met and there was some upset with this

Time was an issue due to workloads



# What was learnt

Implementing change can be exciting but challenging.

I learned some new facilitation skills

How important it is for people we care for to have everyone involved in their care involved





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