

Advance Care Planning: an idea that has come of age?

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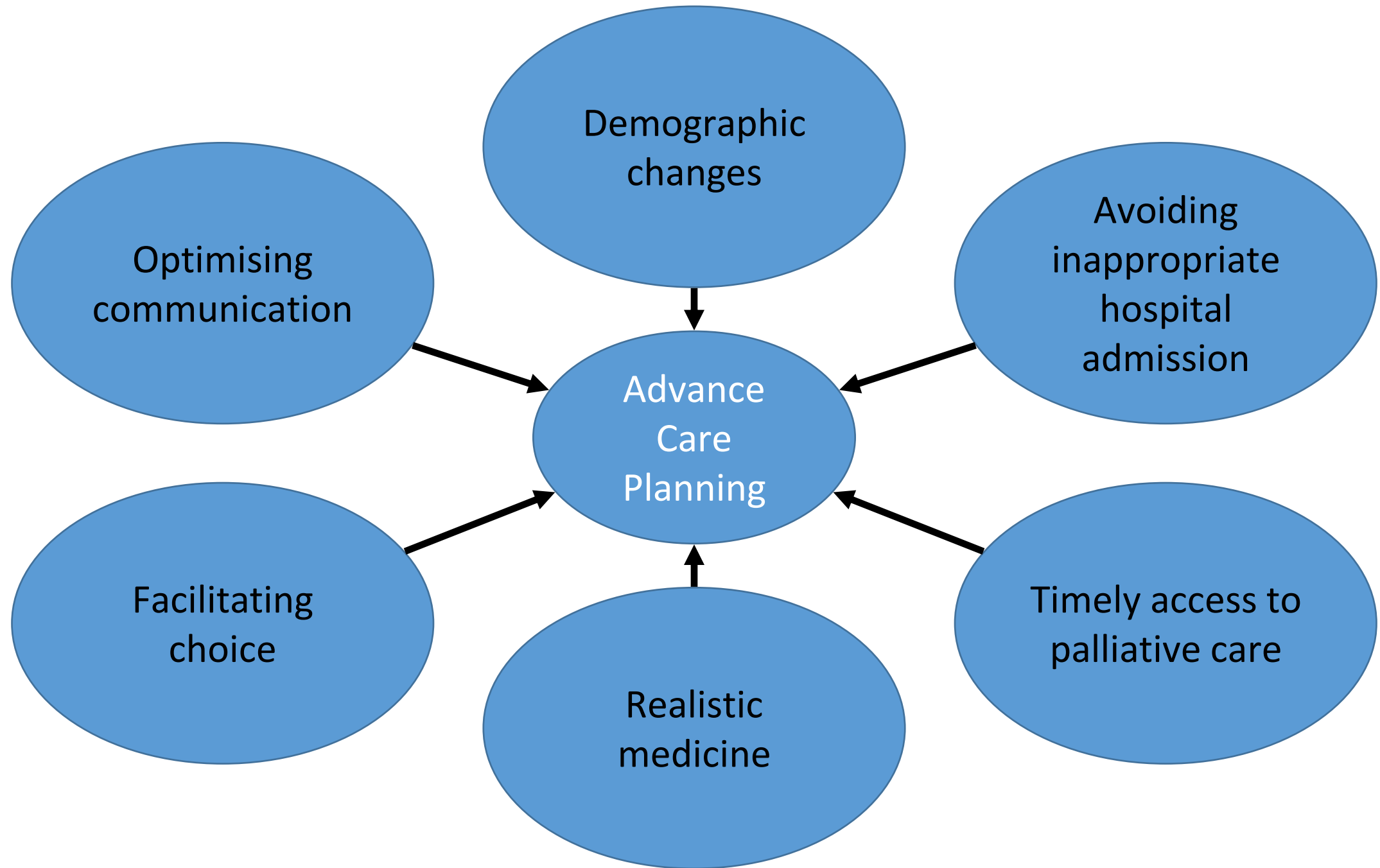
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Definitions

- Advance care planning
- Anticipatory care planning
- Advance directives

What is Advance Care Planning (ACP)?

- An **approach** used to facilitate **discussion** and **documentation** of personal wishes including preferred place of care in the last days of life
- Can be used to **anticipate needs** which may arise when the person concerned no longer has the capacity to **make decisions** about his or her own care (Connolly, Milligan et al 2015).

Features of ACP

- Ongoing discussion
- Involvement of patient, clinician/wider team, family member(s)
- Explores context including beliefs, understandings, hopes and expectations
- Addresses patient-related information needs
- Usually covers care at the end of life
- Usually results in a document (but not always)
- Founded on a good therapeutic relationship.

Anticipatory Care Planning

- Described as adopting a 'thinking ahead' philosophy of care that allows practitioners and their teams to work with people and those close to them to set and achieve common goals that will ensure the right thing is being done at the right time by the right person(s) with the right outcome.
- Commonly applied to support those living with a long term condition to plan for an expected change in health or social status. It also incorporates health improvement and staying well.
- Usually results in completion of a common document called an anticipatory care plan (The Scottish Parliament 2015)..

Advance Directives

- **Legal documents** that allow patients to put their healthcare **wishes** in writing, or to appoint **someone they trust** to make decisions for them, if they become incapacitated (Miller 2017).
- Examples include:
 - Advance Directive (or Decision) to Refuse Treatment (ADRT)
 - Living Will
 - Enduring Power of Attorney..

Some research around ACP (1)

- Advance care planning in elderly hospital patients can deliver:
 - Greater likelihood of end of life care wishes being fulfilled
 - Lower levels of stress and higher levels of satisfaction among family membersDetering, Hancock, Reid et al (2010) Australia
- Advance care planning in out-patients with terminal cancer can result in:
 - No increases in depression or anxiety
 - Lower rates of aggressive interventions
 - Earlier hospice referral
 - Better bereavement experiences for family membersWright, Zheng, Ray et al (2008) US

Some research around ACP (2)

- A concerted approach among hospital patients can deliver:
 - substantial uptake of ACP

Cantillo, Corliss, Ashton et al (2017) Hawaii
- Motivating General Practitioners around ACP can result in:
 - Substantial uptake of ACP
 - Better representation of non-cancer patients
 - Earlier access to palliation

Tapsfield, Hall, Lunan et al (2016) Scotland

Good practice in ACP

- Start as early as possible, while the person is well enough and has sufficient capacity to fully engage (Albayrak, Kahveci, Özkara et al 2014).
- Make use of triggers to initiate or restart the process (Mullick, Martin and Sallnow 2013).
- Commit to discover patients' hopes and fears and to create an individually meaningful framework in which to ground the discussion of goals of care (Rocker et al 2015).
- “the discussion is equally or more important than any document arising from it” (Ibid)..

An example from renal medicine (Rak et al 2017)

Disease stage	Priorities
All stages	<ul style="list-style-type: none">• Involve an interdisciplinary team in the care of patients and their families• Constantly review and refine the Advance Care Plan
Living with chronic kidney disease	<ul style="list-style-type: none">• Initiate a discussion of goals of care• Explore biopsychosocial, cultural and spiritual values• Educate patients and their families about the disease process, especially in the context of multiple comorbidities
End stage renal disease	<ul style="list-style-type: none">• Review goals of care• Consider commencing renal dialysis
End of life	<ul style="list-style-type: none">• Review goals of care• Consider timing for withdrawal of dialysis

An example from respiratory medicine (Rocker et al 2015)

- Build on an existing therapeutic relationship
- Make the ACP conversations themselves part of the care provided
- Agree on broad goals of care
- Explore reliable, alternative, integrated models of care attuned to the person's individual needs
- Make particular plans for dealing with dyspnoea crises (breathlessness attacks) in the form of a written graduated course of interventions
- Share ACP insights with other team members to ensure a broad supportive approach.

Challenges associated with ACP

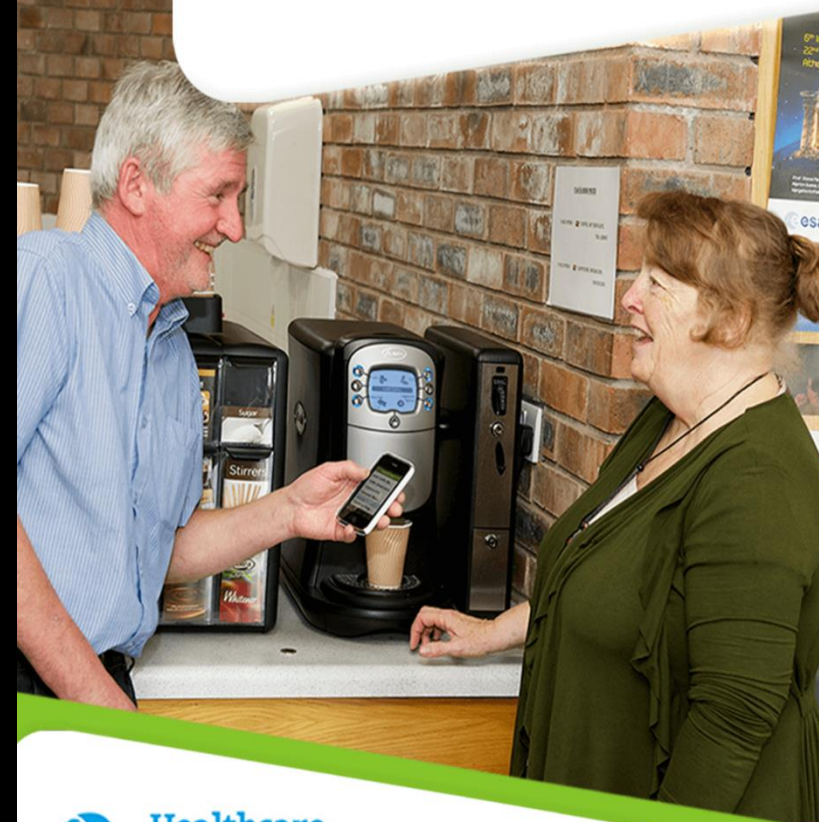
- Personal choice
- Cultural sensitivities
- One or more parties “not ready”
- Locating the ACP when we need it
- Issues around consent and sharing
- Who “owns” the ACP

A Scottish ACP timeline

- Pre 2008: ACP was already an element of the Gold Standards Framework for palliative care in the community
- 2008: Publication of Living and Dying Well: a national action plan for palliative and end of life care in Scotland and the setting up of a short-life working group (SLWG) on ACP.
- 2009: Publication of **position paper** from SLWG on ACP
- 2010: Roll out of NHS Education Scotland Advance / Anticipatory Care Planning **training pack**
- 2012: Incorporation of the Key Information Summary (KIS) into Scottish **GP contract** requirements
- 2013: Widespread adoption of eKIS to improve sharing of the wishes of community patients
- 2015: Publication of Strategic Framework for Action on Palliative and End of Life Care with commitment to support ACP through **eHealth systems**
- 2016: Launch of “Let’s think ahead – My ACP” **app**
- 2017: Establishment of a **national** Anticipatory Care **Toolkit** including “My Anticipatory Care Plan”
<http://ihub.scot/media/2207/my-acp.pdf>

Let's think ahead

My Anticipatory Care Plan



Let's think ahead




My Anticipatory Care Plan



Anticipatory Care Planning (ACP) is about thinking ahead and understanding your health. It's about knowing how to use services better and it helps you make choices about your future care.

Planning ahead can help you be more in control and manage any changes in your health and wellbeing.

Talking to the people who matter to you helps shape the right plan for you.




This is your plan - It's not legally binding in any way, completing it is voluntary. It may be that all parts of this document do not apply to you just now. Complete what is important to you.

Date:

Review date:

It's a good idea to think about updating or reviewing your plan from time to time.



It might be appropriate for the professional who is helping you most to summarise important clinical details in the clinical management plan at the end of your plan.

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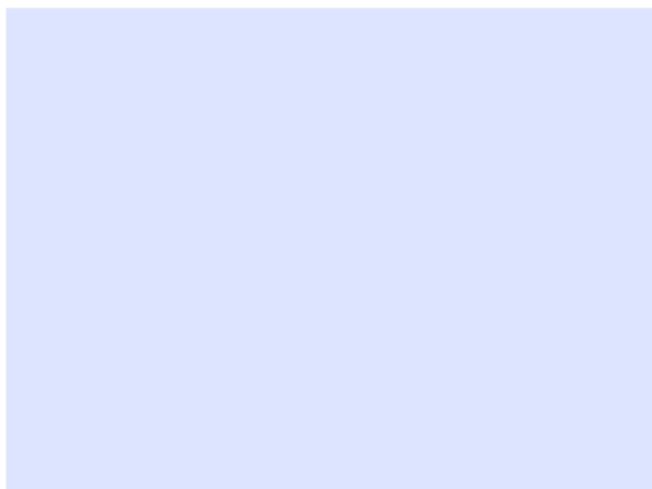
My future plan

If I become more unwell

Staying at home is what many people would prefer when they become unwell. At times, your health may change and you may need to be admitted to hospital or somewhere else other than home. Having a plan in place can help you be more in control of your care.

If I need to be admitted to hospital, the things that are important to me are...

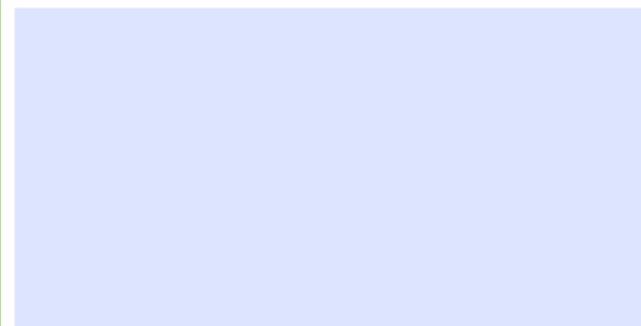
You might need help with any caring responsibilities, other family members, pets, letting your employer know you will be off sick, paying bills or keeping an eye on your house and garden.



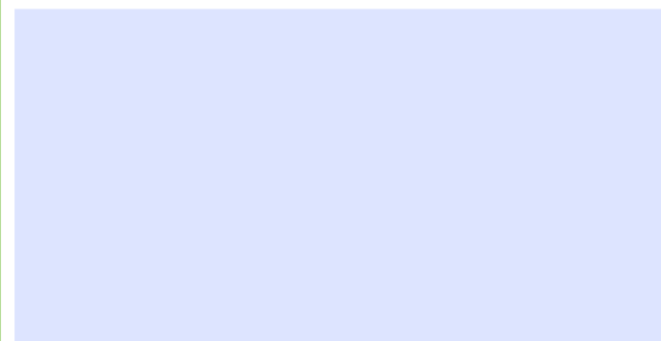
What happens may depend on your situation at the time.

The things I would like for me

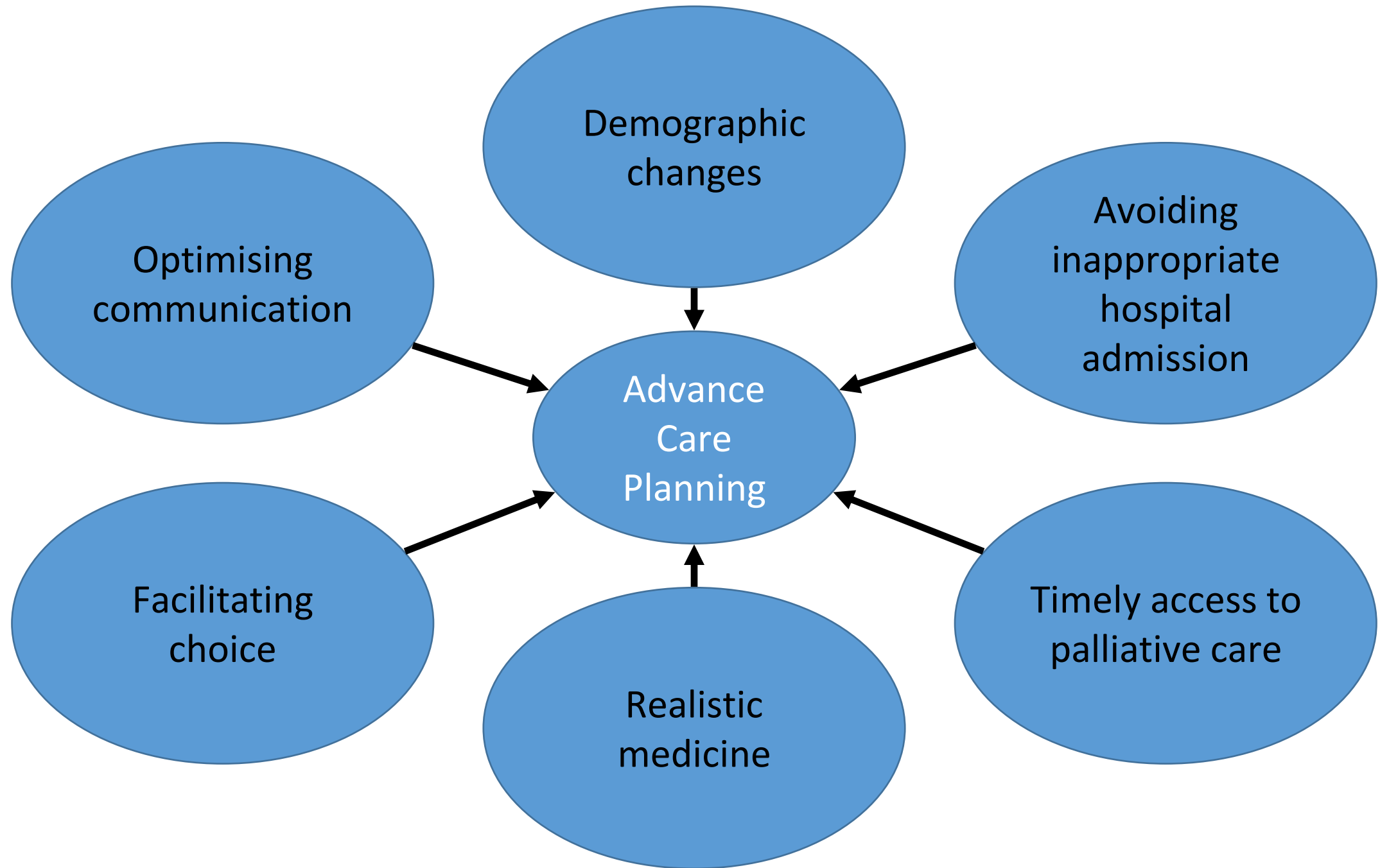
There may be different choices of treatment or care available to you if you become more unwell. The best choice will depend on your situation at the time.



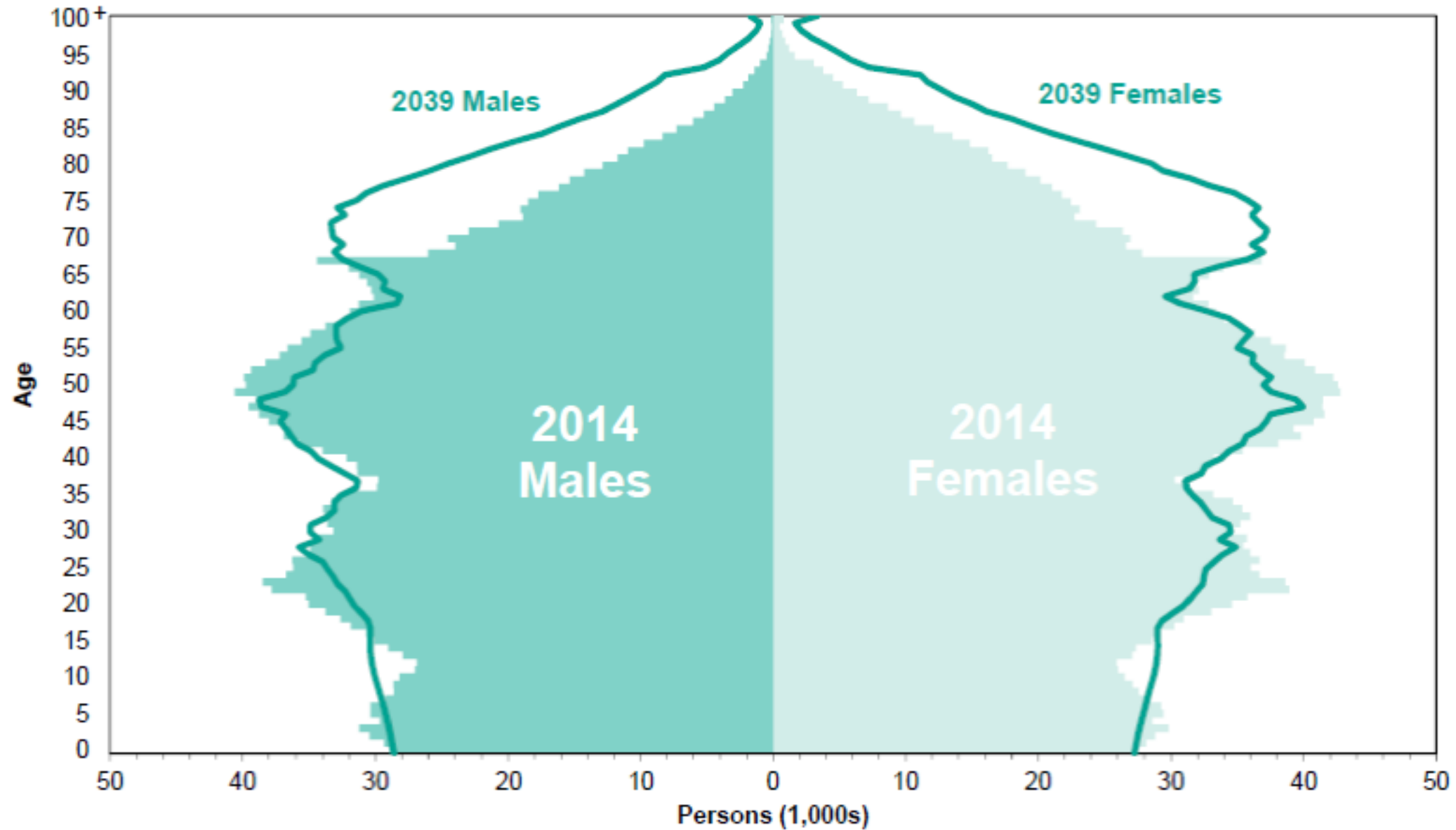
The things I don't want for me



You should always be involved in decisions about your care as much as possible.



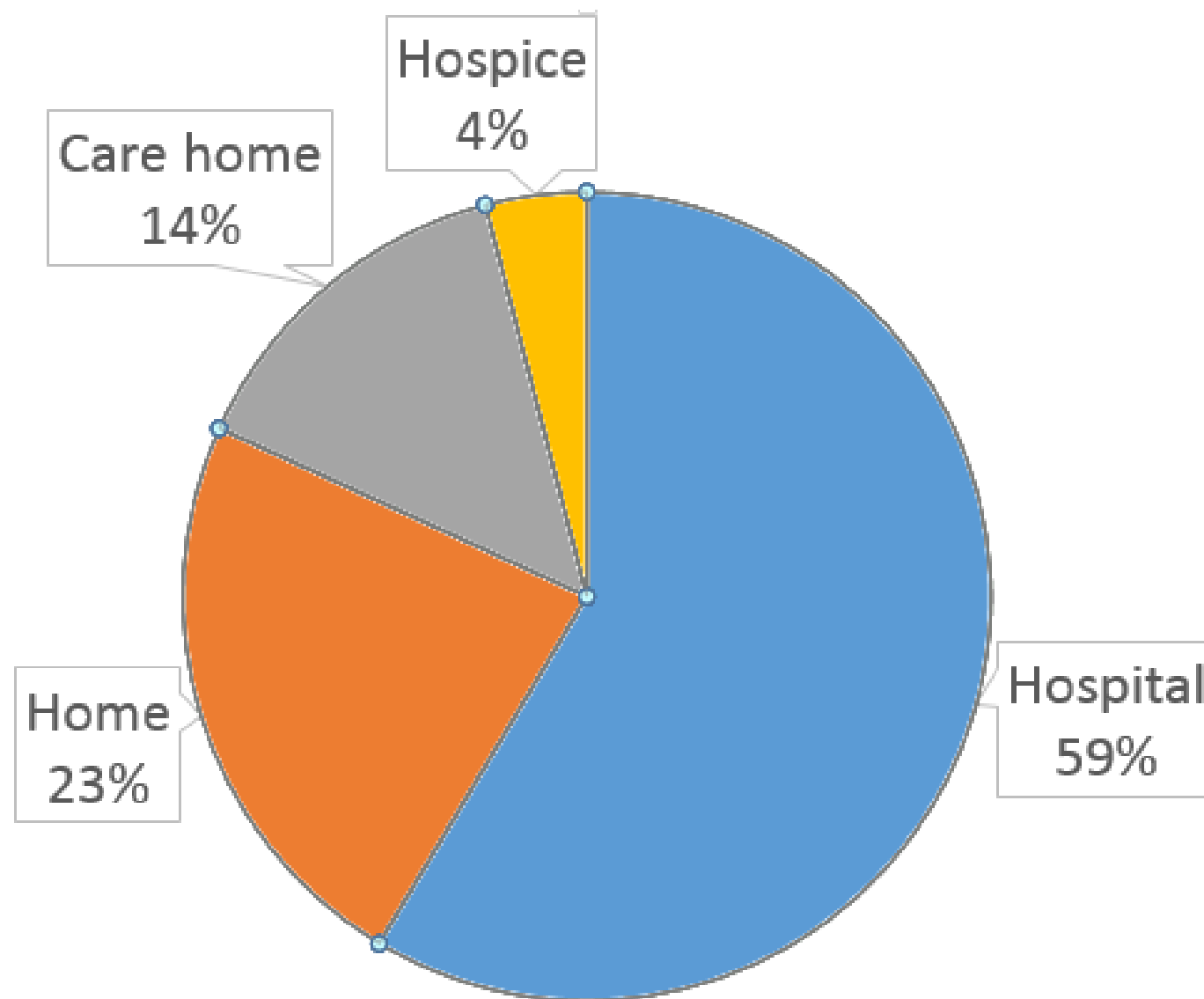
Projected change in age structure of Scottish population 2014 to 2039 (National Records of Scotland 2015).



Percentage of 530 community patients identified for palliative care and referred to specialist palliative care (from Zheng et al 2013)

Diagnosis	Cancer	Organ failure	Dementia / Frailty
Number	200	170	160
Identified for palliative care	75%	19%	20%
Referred to specialist palliative care	69%	11%	5%

Place of death (all causes) in Scotland in 2016 (ISDS)



An idea that has come of age?

Although not without its flaws, Advance Care Planning has the potential to help us work with patients and their families to start addressing some of the major challenges facing palliative care in the 21st Century.

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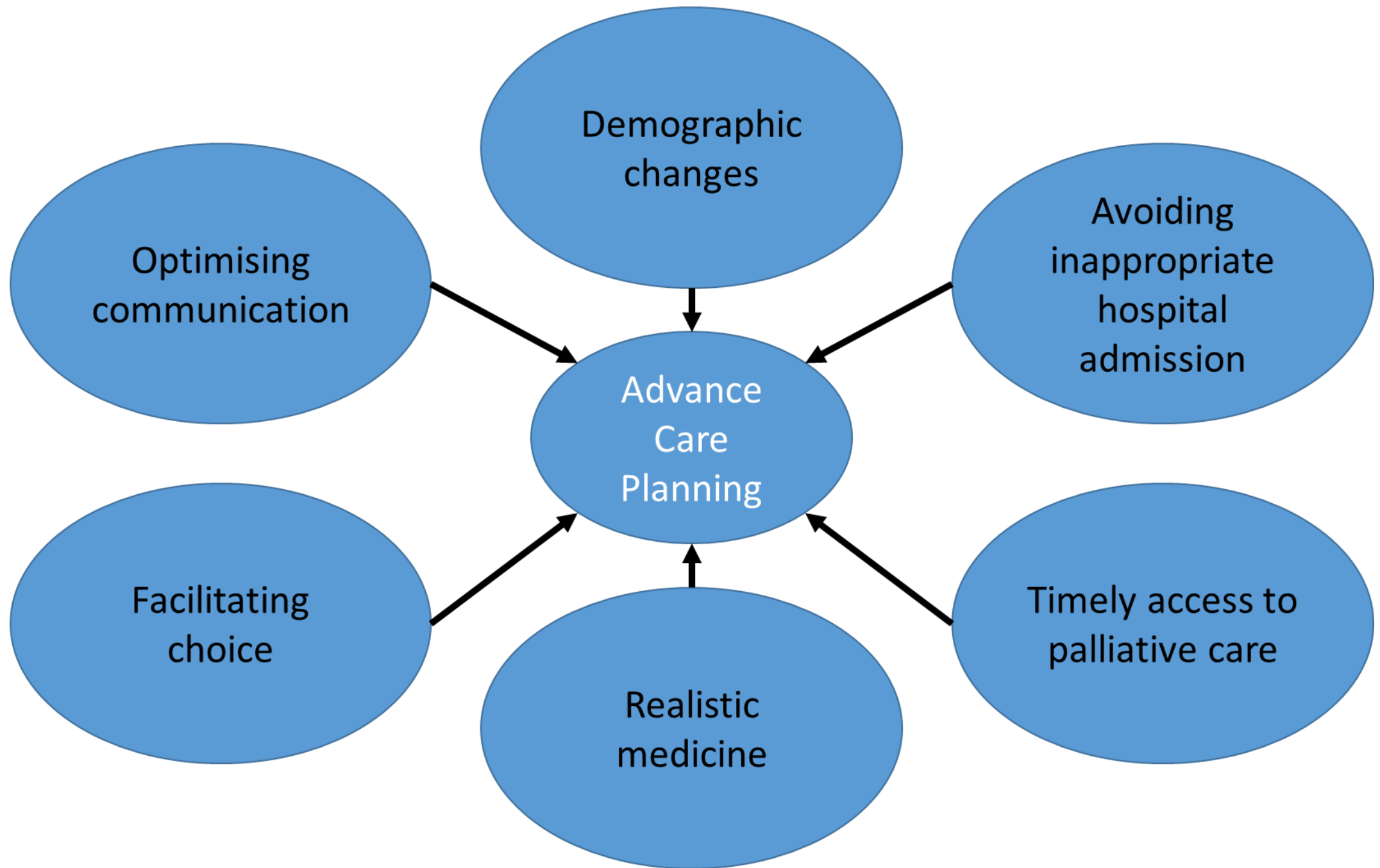
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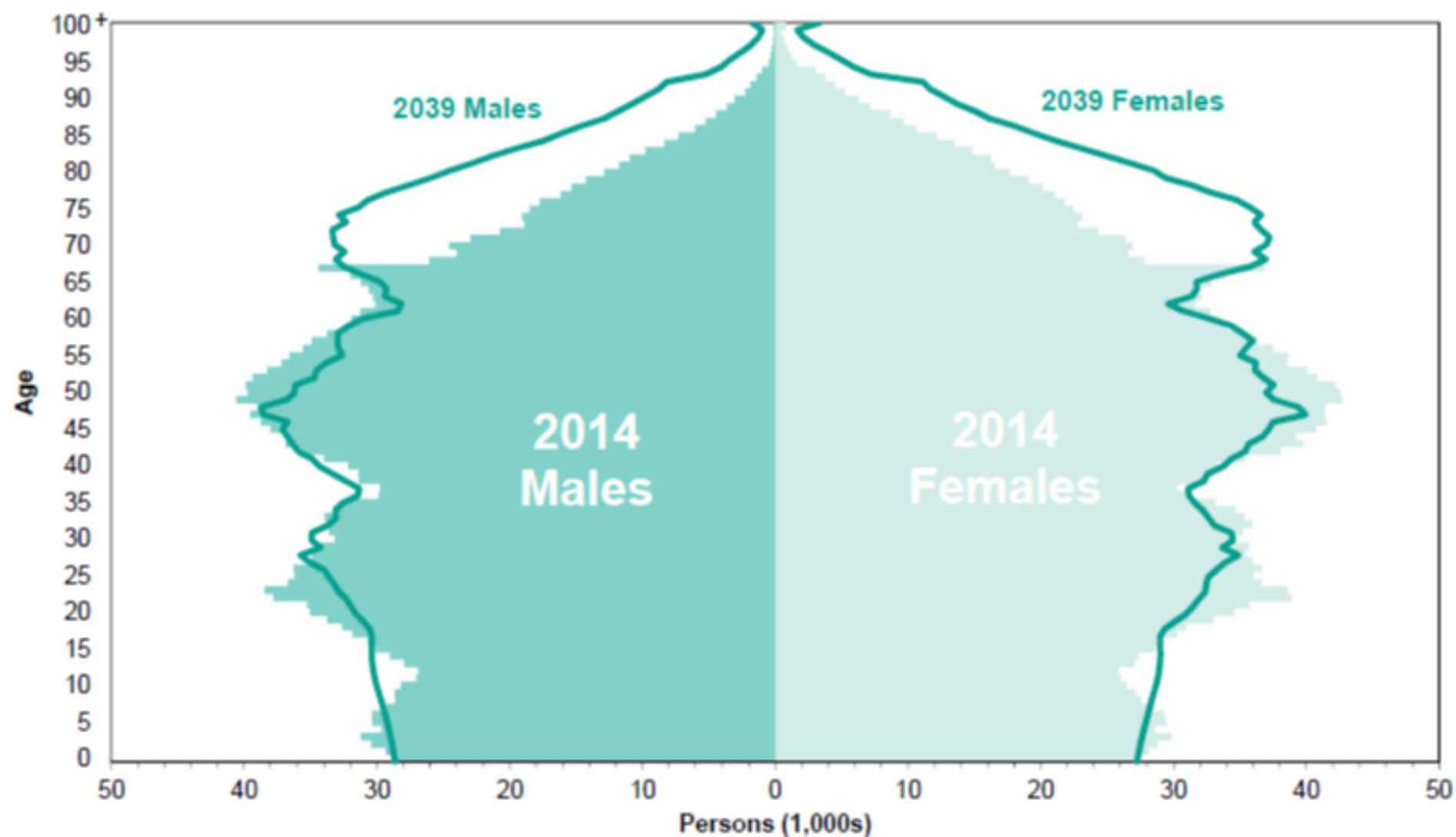
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Back-up slides



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