

Advance Care Planning in Paediatric Palliative Care: A two year review of practice in a UK tertiary paediatric palliative care service

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Overview

- Introduction
- Background
- Results
- Discussion
- Future plans

Introduction

- Evelina London Children's Hospital Paediatric Palliative Care team:
 - specialist palliative care service
 - any child with a life-limiting or life-threatening condition
 - known to Evelina London, Kings, partner DGHs etc. across London and South East England
 - hospital, home, hospice

Geographical spread

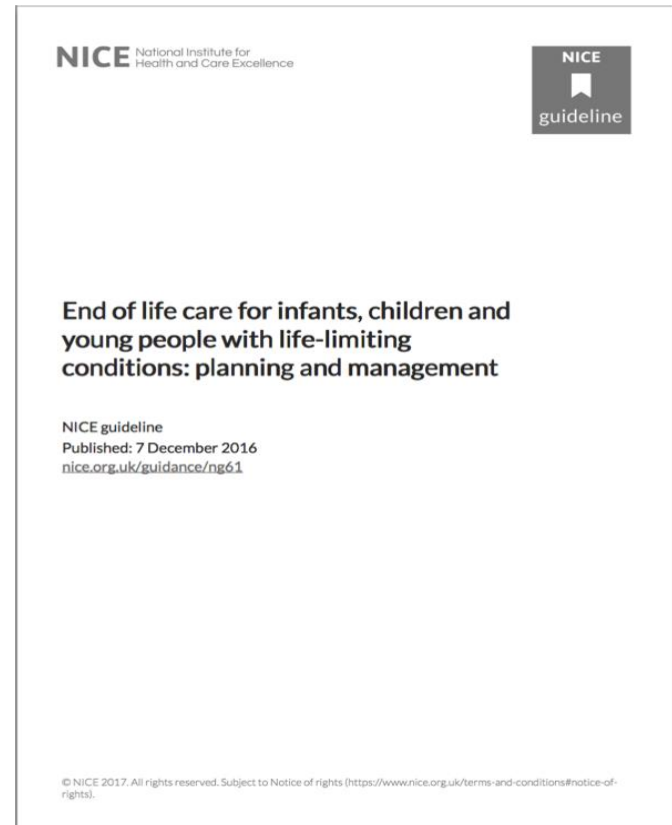


Advance Care Planning

- One of our main areas of work with children and families
- Are we doing it well?
- Are we meeting standards?
- Can we improve?
- If so, how?

Standards

- NICE:
 - Develop and record an Advance Care Plan at an appropriate time for the current and future care of each child or young person with a life-limiting condition
 - = 100% ?



Review of practice

- 2 year review
- September 2015 to December 2017
- All referrals

- Data collected retrospectively, from our database and patient notes:
 - Diagnosis
 - ACP completion
 - Location of care
 - Timing of referral

Results

- 192 referrals
- 80 had ongoing PPC input
- 85 died
- 27 discharged

ACP completion

- In total 63 (33%) of children had an ACP
 - Of the children who died: 35 (41%)
 - Of the children requiring active PPC: 26 (33%)
 - Of the children discharged: 2 (7%)
- Completion rates lower than expected

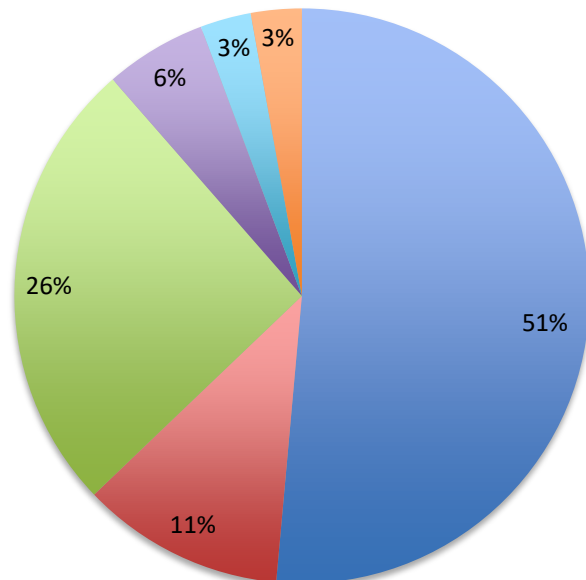
Why the low rate?

- ACP most useful for end of life care
- Emphasis on preference of location of care
 - Important, and able to measure this
- Therefore, analysed the ACP completion rates for children who had died during this period
 - ? Related to diagnosis / specialty
 - ? Related to location of patient
 - ? Related to timing of referral

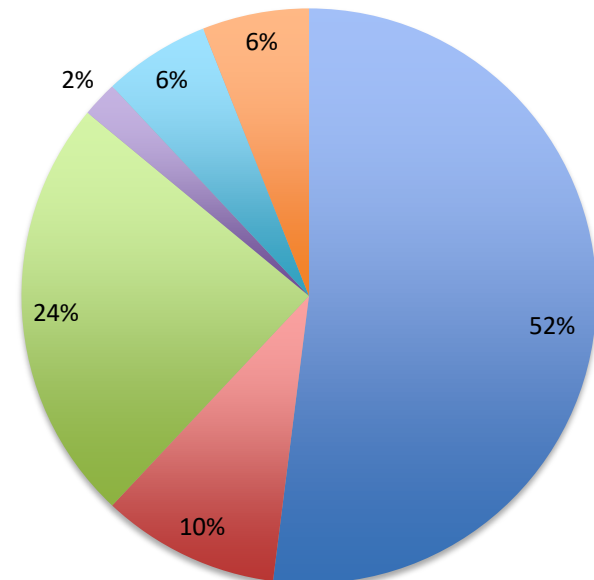
ACP completion vs diagnosis (Deceased group)

- 35 of 85 (41%) had ACP
- 50 of 85 (59%) had no ACP

■ Neuro ■ Metabolic ■ Cardiac ■ Respiratory ■ Multi ■ Renal

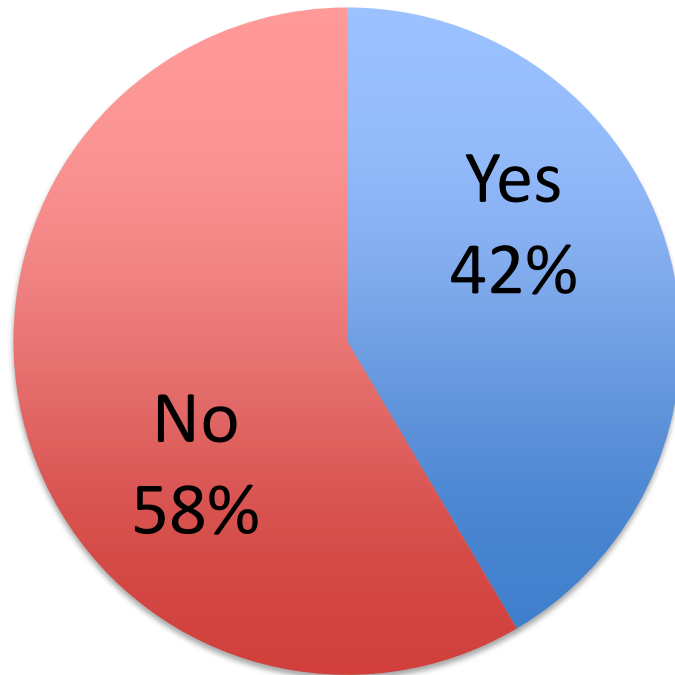


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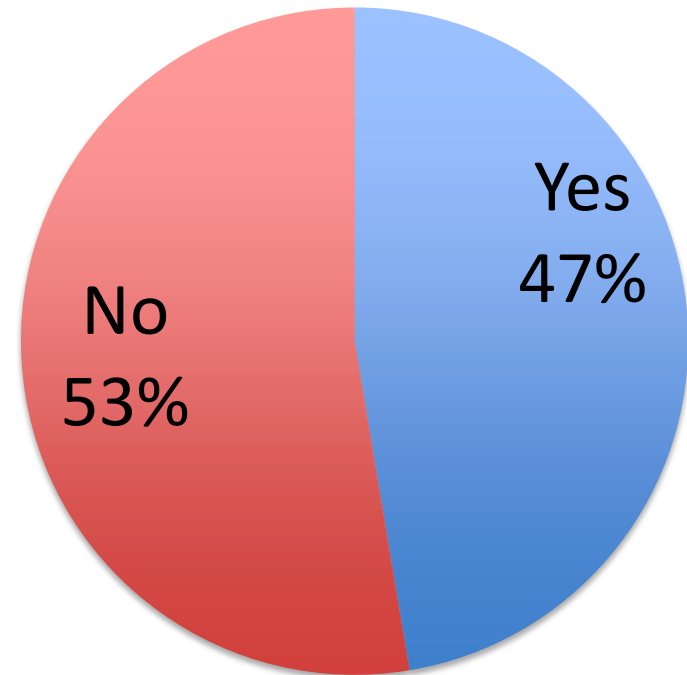


ACP Completion vs diagnosis (Deceased group)

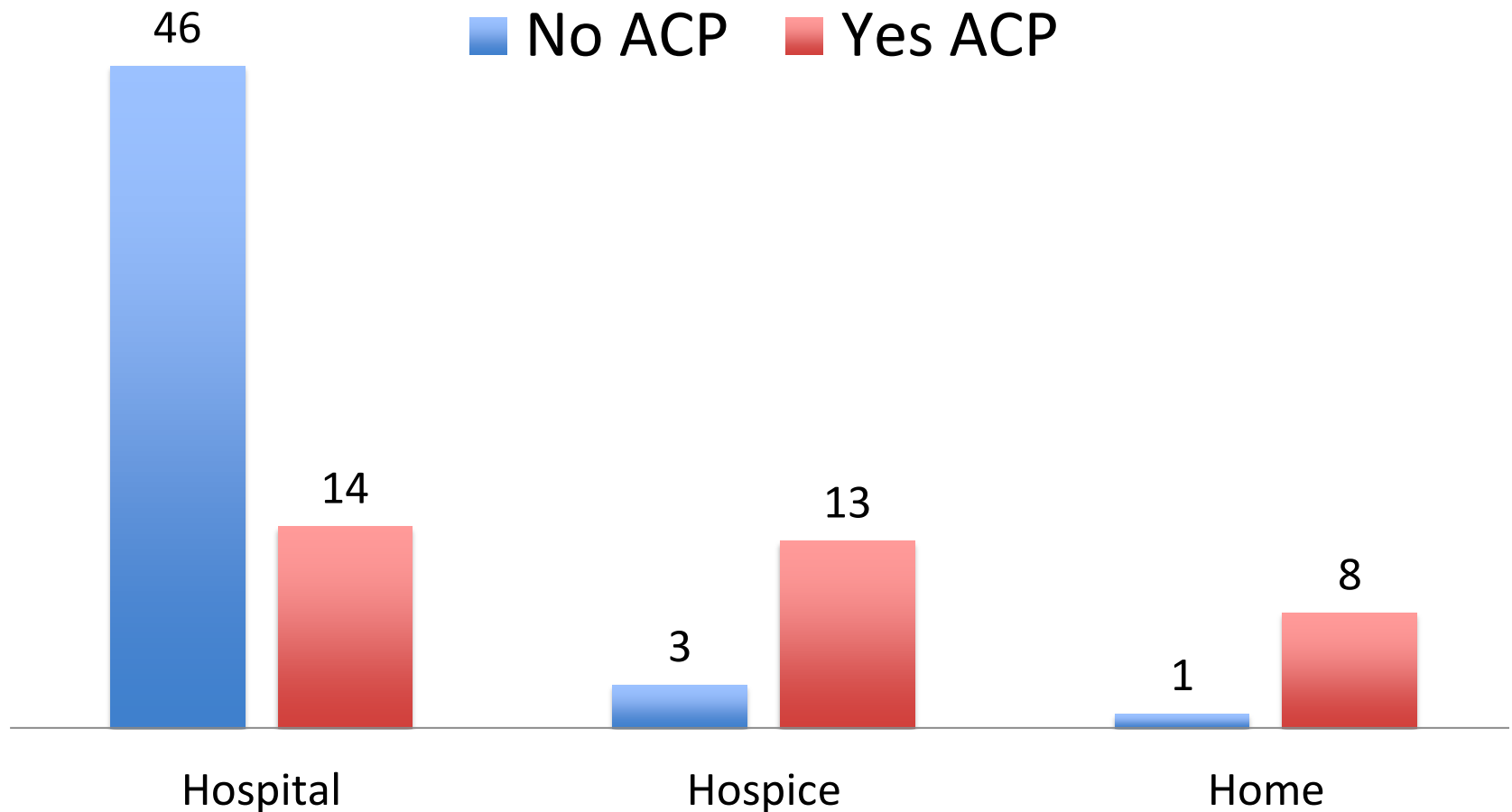
Neurometabolic:



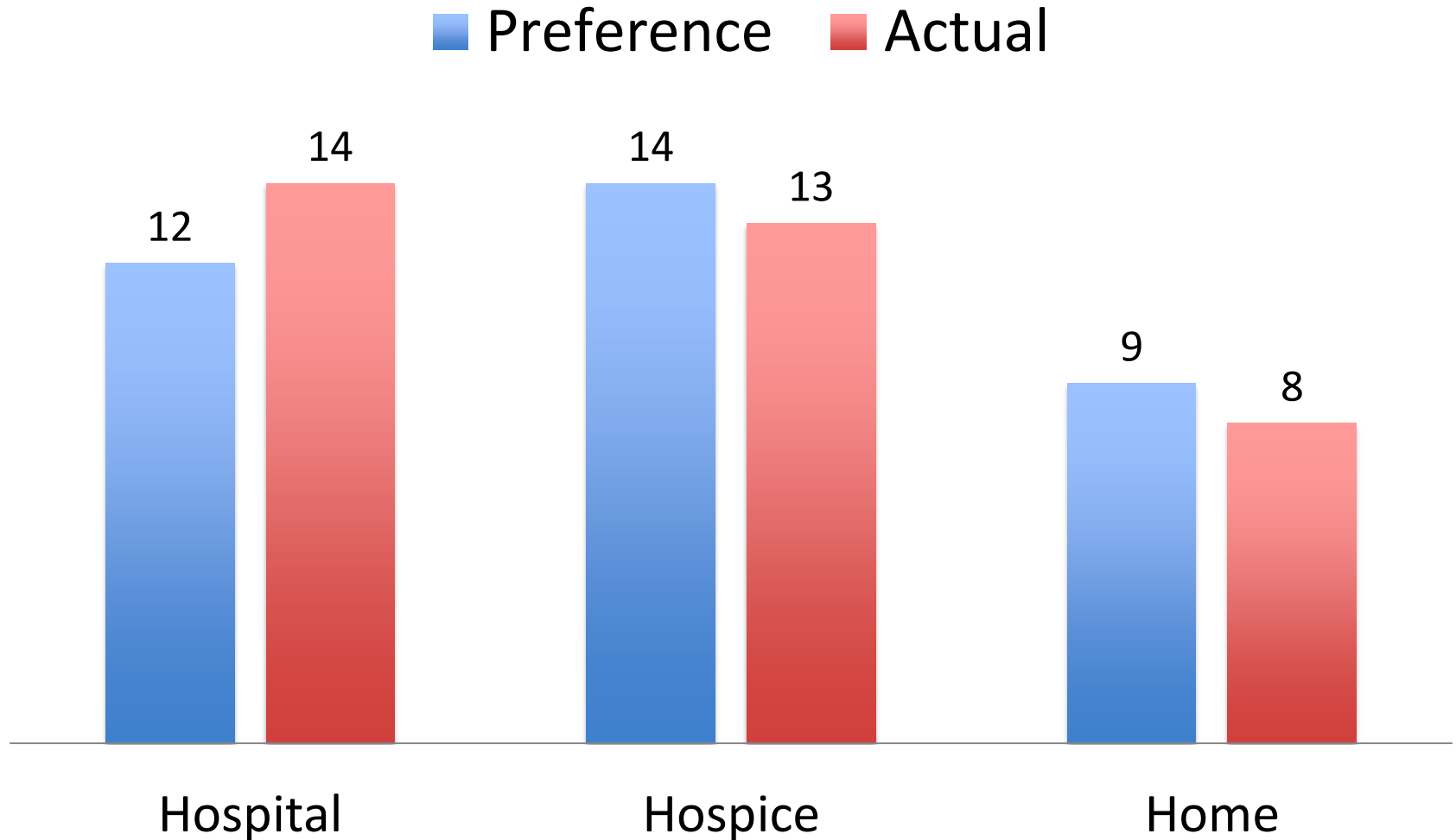
Cardiac:



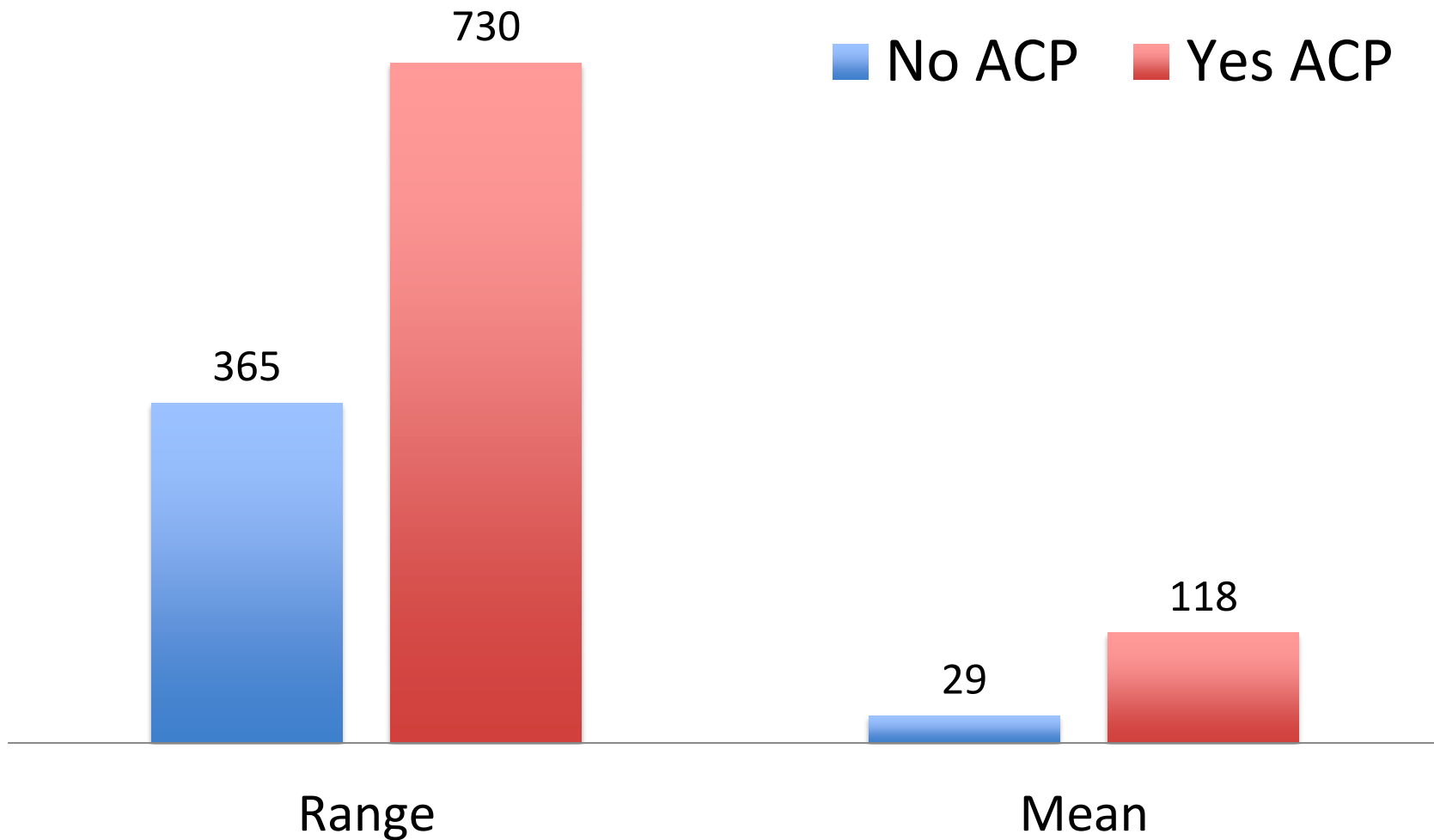
ACP completion vs location of EOL care



Preference for location of EOL care



Days from referral to end of life



Discussion

- Lower ACP completion rates than expected
- No correlation to diagnosis / specialty
- If no ACP, more likely to die in hospital
- If ACP completed, location of care varies
 - Inequitable measuring of location preferences
- ACP group had twice the number of days from referral to end of life
 - Time to build on discussions
 - Not possible for some, sudden deterioration / Compassionate extubations

Future Plans

- To try and improve our ACP completion rates
- Timely referrals
 - Better links with teams
 - Share the findings from this review
 - Increased staffing
 - Time constraints and logistics of transfers out of hospital (pharmacy link, community support)
- Clarify preference for location of care
- Review again in another 2 years

- Thank you
- Any questions?