Complexity and costs in palliative care: the way forward Webinar

Big Conversations Series
27 June 2024

HospiceUK

Agenda		
09:00	Welcome	**Julie Kinley**, Clinical Research & Evidence Manager, Hospice UK
09:35	Complexity in Palliative Care	**Matthew Grant**, Palliative Medicine Physician / Assistant Professor at University Medical Centre Utrecht (Netherlands) and University of Melbourne (Australia)
10:05	The costs of specialist palliative care, and complexity and casemix in the UK	**Fliss Murtagh**, Professor of Palliative Care and Director of the Wolfson Palliative Care Research Centre - Hull, UK
10:40	**BREAK**	
10:50	An Introduction to Community Currency Models	**Gary Stinson**, Payment Development Manager, NHS England
11:20	Q&A	All
11:55 – 12:00	Close	**Julie Kinley**, Clinical Research & Evidence Manager, Hospice UK

Big Conversations

We have launched the Big Conversations which comprises of a series of webinars, workshops, and roundtables that will enable our members to:

- learn more about key issues
- share your knowledge and experience to inform our work
- discuss problems and solutions with your peers
- get practical guidance to move work forward.

We hope that you will join us over the coming weeks and months to find out more about topics such as racial equity and CQC.

Complexity in Palliative Care

Matthew Grant

Palliative Medicine Physician / Senior Research Fellow

UMC Utrecht, The Netherlands

University of Melbourne

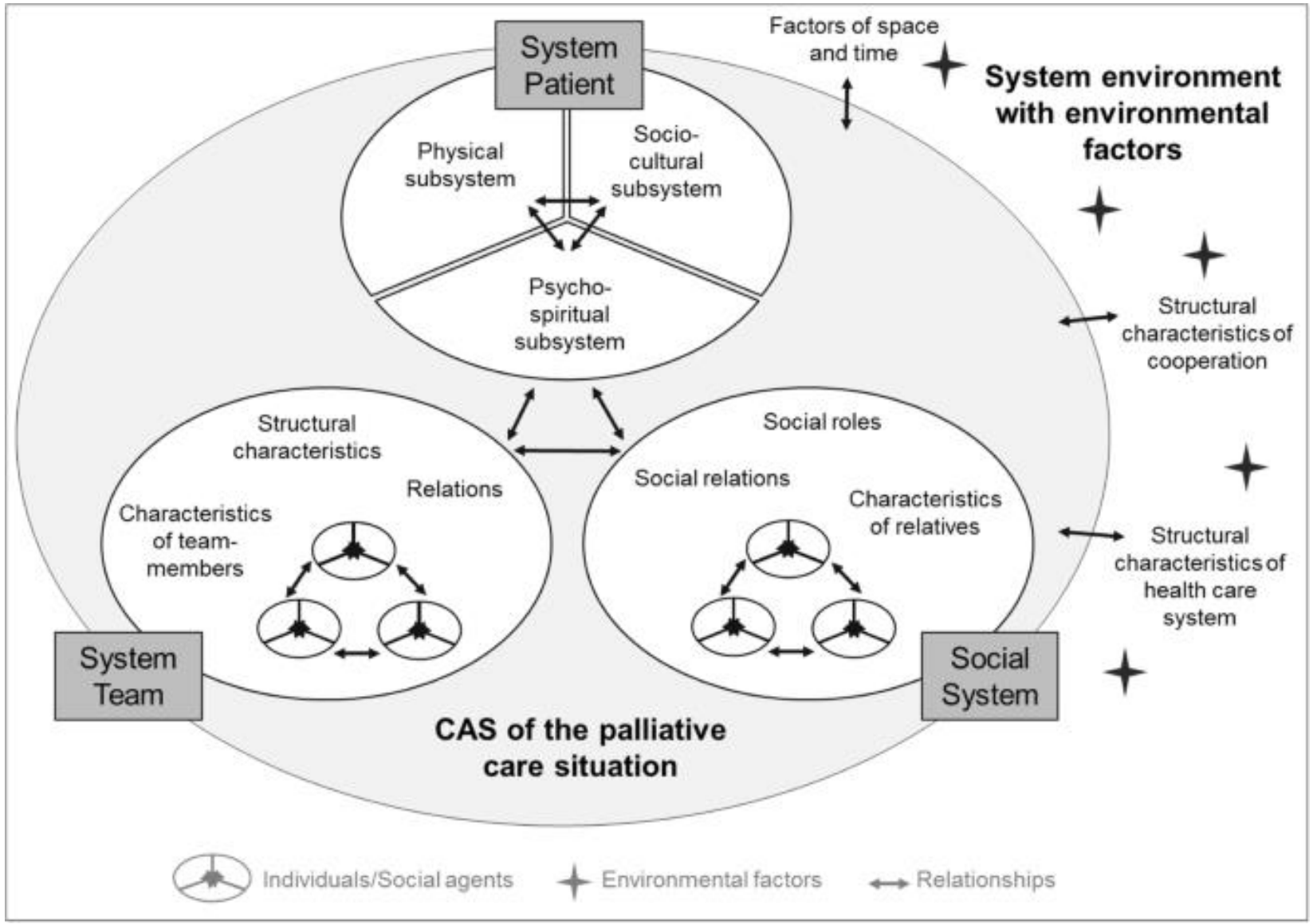
Complexity

” the nature of patients’ situations and the extent of resulting needs and care demands”

- A quick overview of complexity
- Contextualising complexity
  - Australia
  - The Netherlands
- Classifying complexity
- Integrating into practice

Complexity in Palliative Care

- Palliative care provisions is complex
    - Many care providers and teams (formal and informal), longitudinal care processes
- Palliative care patients are heterogenous, vulnerable, with progressive illness trajectories, and many varied impacts on their health and care needs
- The care needs of the patient and carers, and the ability to provide palliative care can change suddenly and dramatically, leading to disruptions or mismatches in the system of care



- To characterize patient situation and the resultant care needs

- Complexity provides a framework to appreciate the many influencing factors impacting the provision of care

1. Hodiamont, F., Jünger, S., Leidl, R. *et al.* Understanding complexity – the palliative care situation as a complex adaptive system. *BMC Health Serv Res* **19**, 157 (2019).

2. Pask, S., Pinto, C., Bristowe, K., Van Vliet, L., Nicholson, C., Evans, C. J., ... & Murtagh, F. E. (2018). A framework for complexity in palliative care: a qualitative study with patients, family carers and professionals. *Palliative medicine*, *32*(6), 1078-1090.

Applying complexity

What are its applications in real life?

- Assist in understanding patient needs
  - Improving patient assessment
  - Inform treatment and care planning decisions
- Identifying complexity of care needs
  - Needs for generalist / specialist services
  - Triage.
- Casemix classification
  - Guide resource allocation
  - Staffing
  - Reimbursement

Australia

- PC is a medical specialty, with specialist community teams (metropolitan)
    - specialist PC primarily accessed by cancer patients
    - less GP usage than England and NL (3).
- Australia has relatively few PCU/hospice beds per population = 80-90 hospices
    - PCU often functioning as acute units.

3. Grant, M., et al. "Primary care usage at the end of life: a retrospective cohort study of cancer patients using linked primary and hospital care data." *Supportive Care in Cancer* 32.5 (2024): 273.

- Australia was the first country to integrate complexity classifications into routine clinical practice
    - Australian National subacute and non-acute patient classifications (AN-SNAP)
    - Classification of resource usage
- Due to poor availability of beds, need for triage for patients with greatest needs

Original Article

PALLIATIVE MEDICINE

Validation of the responding to urgency of need in palliative care (RUN-PC) triage tool

Palliative Medicine
2021, Vol. 35(4) 759–767

DOI: 10.1177/0269216320986730
journals.sagepub.com/home/pmj
SAGE

Bethany Russell[1,2], Jennifer Philip[1,2,3,4], Olivia Wawryk[1,5], Sara Vogrin[6], Jodie Burchell[6], Anna Collins[1], Brian Le[3,4], Caroline Brand[7,8], Peter Hudson[9,10,11] and Vijaya Sundararajan[5,6]

The Netherlands

Diverse of array of health care professionals and volunteers provide this care

- PC primarily provided by GPs

Hospices - ±300 hospices

- 3 types of hospices – specialist / nursing home / volunteer
- <3month life expectancy to access hospices

Community

- Care provided by GPs, home care, and community nursing
- 40% of patients die at home

Hospital

- No PCU units, often PC consult teams

Lots of beds, but limited specialist services

- Funding is the same per patient

Lots of beds, but limited specialist services

- Variability in care providers
- Structural variability of care systems
- Funding system – per bed per day

1. Are patients with complex needs preferentially accessing specialist services?
 - *How can we identify the complexity of patient's needs?*

2. Health service planning – specialist services for patients with needs / reimbursement
"the right care for the right patient"

Original research

Hospice Care Access: a national cohort study

Everlien de Graaf,[1] Frederieke van der Baan,[1] Matthew Paul Grant ,[1] Cathelijne Verboeket,[1] Merel van Klinken,[1] Adri Jobse,[1] Marieke Ausems,[2] Carlo Leget,[3] Saskia Teunissen[1]

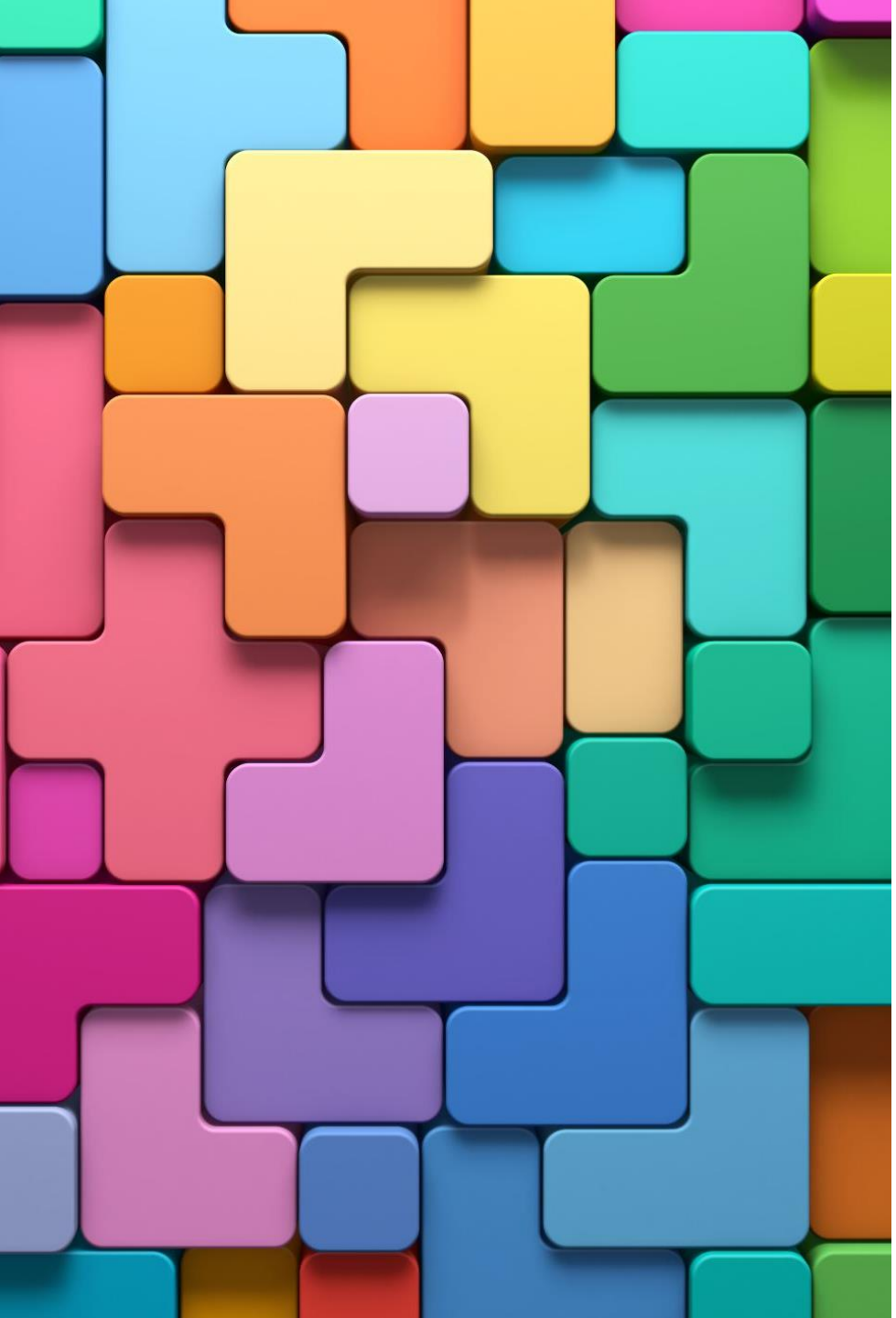
Medical Manuscripts

Variations in Clinical Practice: Assessing Clinical Care Processes According to Clinical Guidelines in a National Cohort of Hospice Patients

American Journal of Hospice & Palliative Medicine®
2022, Vol. 0(0) 1–9

DOI: 10.1177/10499091221100804
journals.sagepub.com/home/ajh
SAGE

Everlien de Graaf, PhD[1], Matthew Grant, PhD[1], Frederieke van de Baan, PhD[1], Marijke Ausems, MSc[2], Cathelijne Verboeket-Crul, MSc[3], Carlo Leget, PhD[4], and Saskia Teunissen, PhD[1]



Review Article

PALLIATIVE MEDICINE

Palliative Medicine
1–15

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A systematic review of classifications systems to determine complexity of patient care needs in palliative care

Matthew Grant[1,2], Everlien de Graaf[1] and Saskia Teunissen[1]

What tool/systems exist to classify complexity in clinical practice?

Classification systems

Classification systems, or casemix classifications are designed to systematically determine the level of patient care needs; thus, classifying patients according to their complexity.

- Used in many acute care settings, but primarily diagnostic based (ie. ICU)
- Predict resource usage

Ideal system in Palliative Care:

- Easy to incorporate into clinical care
- Incorporate different domains of care needs
- Can identify current and predict near-future care needs / resource usage

Table 2. Summary of the classification systems.

Classification system	Classification objectives	Number of items	Patient domain items		Care team domain items	Social domain items	Environmental domain items	Assessment tools used (individual items are described under their specific domain)	Grading
			History and function	Symptoms					
HexCom	To distinguish between those with specialist PC needs	18 Items		Severity physical symptoms Emotional state Risk factors of psychological vulnerability Feeling loved Confident facing unknown Coherency of being	Desire for hastened death Resource limitations Managing basic care needs Communication	Family support External support networks Risk for bereavement Emotional state of family	Access to care Financial resources planning for death Ability to manage death in care environment		Three levels – High/Medium/Low complexity. High or medium complexity require community team intervention
Perocca scale	To evaluate the complexity of care provision	13 Items	Mobility Limb movement Feeding Self-care Elimination	Wound or skin issues Altered conscious state	Frequency of observations Education needs Intravenous therapy Communication difficulties Behavioural issues Requiring oxygen				Four levels of complexity – minimal, intermediate, semi-intensive, intensive
AN-SNAP palliative care	To classify casemix in accordance with health resource use	9 Items total	Phase of illness Mobility Toileting Eating Transfers	Pain Other Sx Psychospiritual Sx		Family or carer distress		RUG-ADL PC Problem severity score (PCPSS)	11 Classification for inpatient, 22 for community
Hui major criteria	To determine need for specialist versus general palliative care	11 Items	Poor prognosis Progressive disease despite chemotherapy Brain metastases or leptomeningeal disease Spinal cord compression or cauda equina	Delirium Spiritual or emotional crisis Severe physical Sx Severe emotional Sx	Request for specialist PC Request for hastened death Assistance with decision-making and planning				Two levels – complex (requiring specialist PC) or non-complex (general PC)

(Continued)

Table 2. (Continued)

Classification system	Classification objectives	Number of items	Patient domain items		Care team domain items	Social domain items	Environmental domain items	Assessment tools used (individual items are described under their specific domain)	Grading
			History and function	Symptoms					
IDC-Pal	To diagnose and stratify complexity, and recommends need for specialist PC	36 Items (35 patient items and one item to add up total score)	Paediatric patient Addiction issues Previous disability Mental illness Patient is a health professional Significant social role Abrupt change in functional autonomy	Difficult Sx Refractory Sx, Urgent terminal Sx Difficult to control terminal Sx Progressive clinical situation Decompensated organ failure Severe cognitive Sx Severe constitutional Sx Difficult to Mx comorbidity Suicide risk Inadequate emotional coping Spiritual suffering	Communication conflicts with health care team Request for hastened death Limitations in professional competence Difficulty in coordination of services Non-compliance issues Difficult palliative sedation Difficult medication Mx Difficult interventions	Family communication conflict Family or carer burden Complex bereavement Inadequate family support Lack of carer competence Dysfunctional family	Environmental limitations Difficulty accessing material or techniques		Three levels – Non-complex – no need for specialist PC. – Complex – potential role for spec PC – High complex – spec PC recommended
PALCOM 1	To assess complexity in palliative care, to manage referral to specialised PC services	24 Items	Karnofsky performance status	Mechanism of pain Pain characteristics Previous narcotic use Cognitive function Psychological distress Presence of pain Asthenia Anorexia Nausea & Vomiting Constipation Dyspnoea Somnolence Insomnia Anxiety Depression	Conflict of information Discrepancies regarding proportionality of treatment Loss of desire to remain alive or hasten death Wish for euthanasia	Absence of carer Carer limitations due to physical health Carer limitations due to work obligations Another person in family requiring care Carer overload Conflict within family		Karnofsky Performance scale Edmonton Classification System for Cancer Pain (ECS-CP)	Three levels – Low Complexity, for general PC – Medium Complexity, for specialised PC – High complexity, for specialised PC

PC: Tool – palliative care; Sx: Symptoms; Mx: Management.

Complexity in Practice

To understand complexity is complex

- Applying the concept of complexity to clinical care can provide a broader understanding of the patient's situation and impacts.

Classification systems

- all utilise prospective questionairres

- 9-35 items

"Although six classification systems have been developed, they access differing aspects of care needs and their application has been limited. The HexCOM and IDC-Pal systems offer the broadest determinations of complexity."

Conclusions

- Complexity is a highly useful concept to apply to palliative care, to assist in:
  - Understanding patient needs and impacts
  - Guide care planning
  - Assist in health service planning
- Applying classification systems in practice is challenging, requiring a prospective approach
- It can be applied in different setting / countries to address some of the challenges of health service planning in palliative care

The costs of specialist palliative care, and complexity and casemix in the UK

Fliss Murtagh, Professor of Palliative Care and Director of the Wolfson Palliative Care Research Centre

HospiceUK

Break

We will be starting again at 10:50

HospiceUK

An Introduction to Community Currency Models

Gary Stinson
Payment Development Manager
NHS England

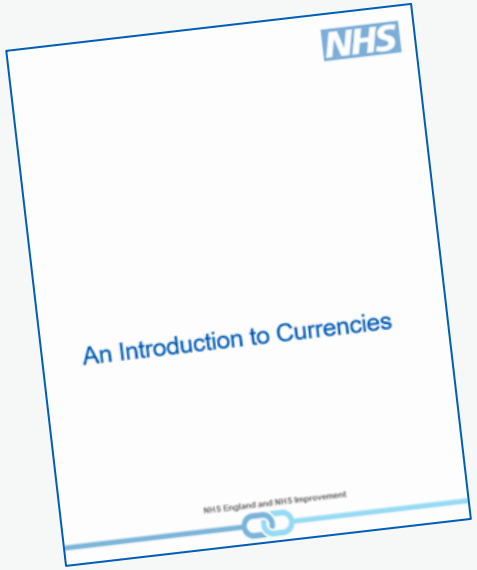
27/06/2024

Pre-Election Period

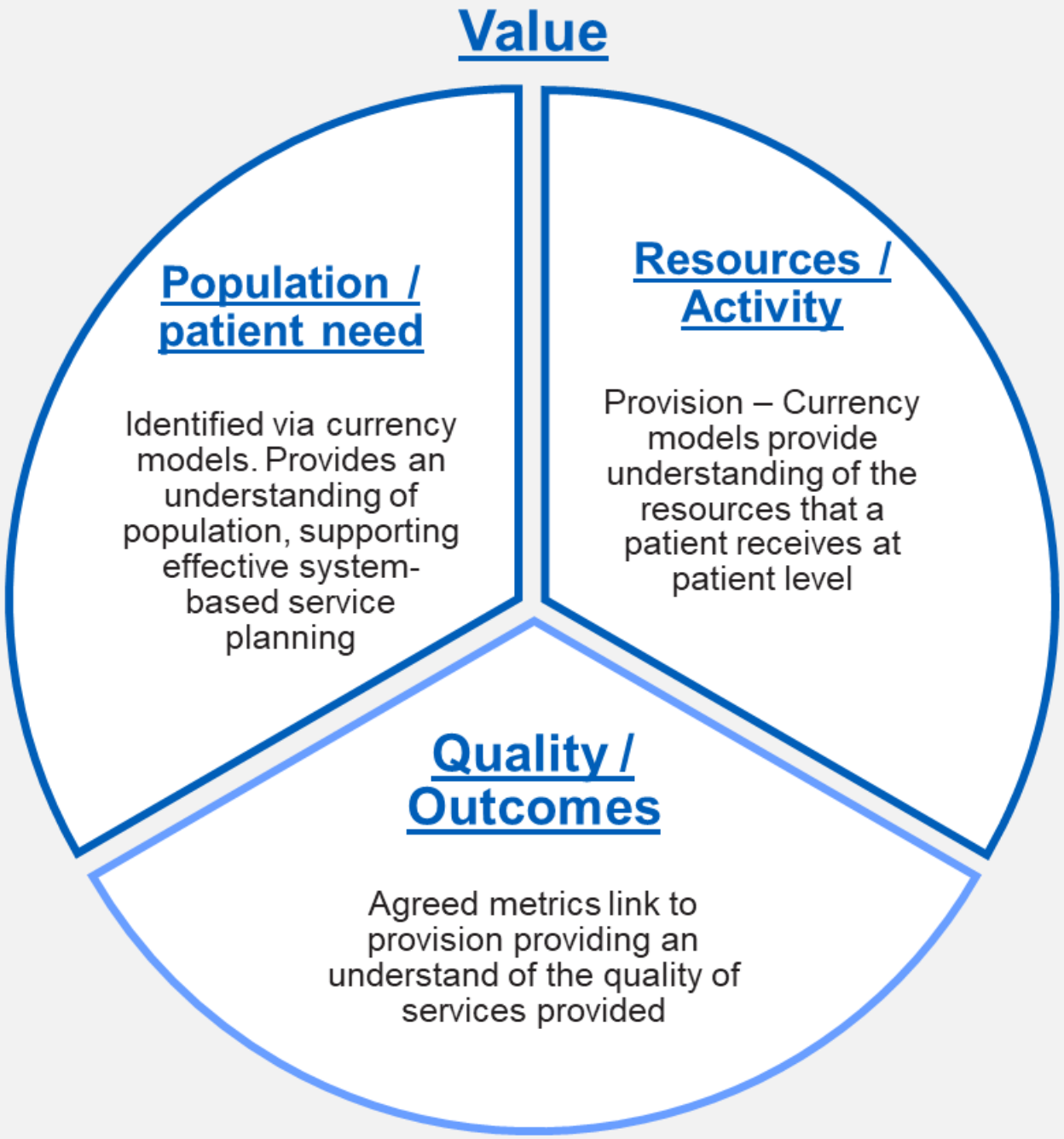
- Guidance in place for NHS Organisations during the election period.
- For today’s session we will focus on our approach and aims of our currency development work.
- Post-election we are going to be engaging more widely on future plans and there will be opportunities for discussion to follow on from this presentation.

What is a Currency?

- A way of grouping patients' activities into units that are clinically similar and have broadly similar resource needs and costs.
- Each unit of currency must be evidence-based and analytically identifiable, but most importantly it must be clinically meaningful.
- The currency must be rooted to the care the patient receives and be practical to implement.
- A currency model provides a structured way to classify a population based on specific attributes such as needs.



Our vision is for currency models - to be a tool for understanding the value of care for clinicians, commissioners, policy



How can currencies support Community Services?

Patient Level

- Provides a standardised method of mapping a patient journey or trajectory over a period of time.
- Consistent complexity assessments can be applied for patients moving between providers and/or services.

Provider Level

- Provides an understanding of the local patient population and complexity of this population, supporting a population health management approach.
- Supports a better understanding of trends within a service and specific gaps in care provision.
- Provides standardised data which supports conversations with other providers and commissioners.
- Ensures independent and community providers have data which is comparable with acute providers.

How can currencies support Community Services?

ICS Level

- Enables an understanding of population complexity which will facilitate decision making on allocation of resources across an ICS footprint.
- Data equity across a system, evidences the need for investment and equity in all parts of the system.

National Level

- An understanding of local and national issues and overall changes in data over time.
- Data can be used to support national policy or targeted support.

Why Use Currency Models?

Currency models are useful tools to understand patient care and compare care across various boundaries. However, the root of any currency model is standardised data.

Using standardised data is the cornerstone of collaborative working, ensuring we understand consistent terms for:

- Patient and referral data
- Diagnosis
- Contact information
- Activities
- Assessments

Knowing we are using the same terminology supports data sharing, ensuring there is confidence in the data received.

We can use this in various ways:

- Cross-provider
- Understanding simultaneous referrals
- Considering and influencing outcomes
- Beyond health

Understanding the Whole Patient

Our aim is to have a set of currency models that cover every person that interacts with community services

- Short Term Interventions
- Long Term Conditions
- Frailty
- Last Year of Life
- Virtual Wards

- CYP Disabilities and Long Term Conditions
- CYP Short Term Interventions
- CYP Palliative and End of Life Care
- Wheelchairs

Last Year of Life Currency Model (Adults)

Applying a currency for patients in their Last Year of Life (LYOL)

Our population is defined using the following definition:

- LYOL population is defined as those people identified as in the last year of life, receiving end of life care. There is an expectation that they will have a personalised care plan and be entered on a supportive and palliative care register.
- LYOL applies to those deaths that can be anticipated and therefore a person's choices can be planned and prepared for.

The currency model uses two assessments as a methodology of understanding patient complexity and need:

Phase of Illness

An assessment which measures the distinct stages of an individual's illness. This measures of patient's own needs, the needs of their family/carers, and their current environment and care plan.

Australian Modified Karnofsky Performance Scale (AKPS)

An assessment which measures a patient's functional status and ability to perform daily living activities.

Phase of Illness

Phase	Start of Phase	End of Phase
Stable	Patient problems and symptoms are adequately controlled by established plan of care and • Further interventions planned to maintain symptom control and quality of life and • Family/carer situation is relatively stable and no new issues are apparent	The needs of the patient and or family/carer increase, requiring changes to the existing care plan (i.e. the patient is now unstable, deteriorating or terminal)
Unstable	An urgent change in the plan of care or emergency treatment is required because: • Patient experiences a new problem that was not anticipated in the existing plan of care, and/or • Patient experiences a rapid increase in the severity of a current problem; and/or • Family/ carers' experience changes which impact on patient care	• The new care plan is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. the patient is now stable or deteriorating) and/or • Death is likely within days (i.e. patient is now terminal)
Deteriorating	The care plan is addressing anticipated needs but requires periodic review because: • Patient's overall function is declining and • Patient experiences an anticipated and gradual worsening of existing problem and/or • Patient experiences a new but anticipated problem and/or • Family/carers experience gradual worsening distress that is anticipated but impacts on the patient care	Patient condition plateaus (i.e. patient is now stable) or • An urgent change in the care plan or emergency treatment is required and/or • Family/ carers experience a sudden change in their situation that impacts on patient care, and requires urgent intervention (i.e. patient is now unstable) or • Death is likely within days (i.e. patient is now terminal)
Dying	Death is likely within days	• Patient dies or • Patient condition changes and death is no longer likely within days (i.e. patient is now stable, or deteriorating)
Deceased	Patient has died; bereavement care provided to family/carer is documented in the deceased patient's clinical record.	

Australian-Modified Karnofsky Performance Scale (AKPS)

Status Score	Descriptor
High	**100%** → Normal no complaints; no evidence of disease **90%** → Able to carry on normal activity; minor signs or symptoms of disease **80%** → Normal activity with effort; some signs or symptoms of disease
Medium	**70%** → Cares for self; unable to carry on normal activity or to do active work **60%** → Requires occasional assistance, but is able to care for most personal needs **50%** → Requires considerable assistance and frequent medical care
Low	**40%** → In bed more than 50% of the time **30%** → Almost completely bedfast **20%** → Totally bedfast and requiring extensive nursing care by professional and/or family **10%** → Comatose or barely arousable **0%** → Dead

Last Year of Life Currency Model

The combination of these two assessments provides the following currencies:

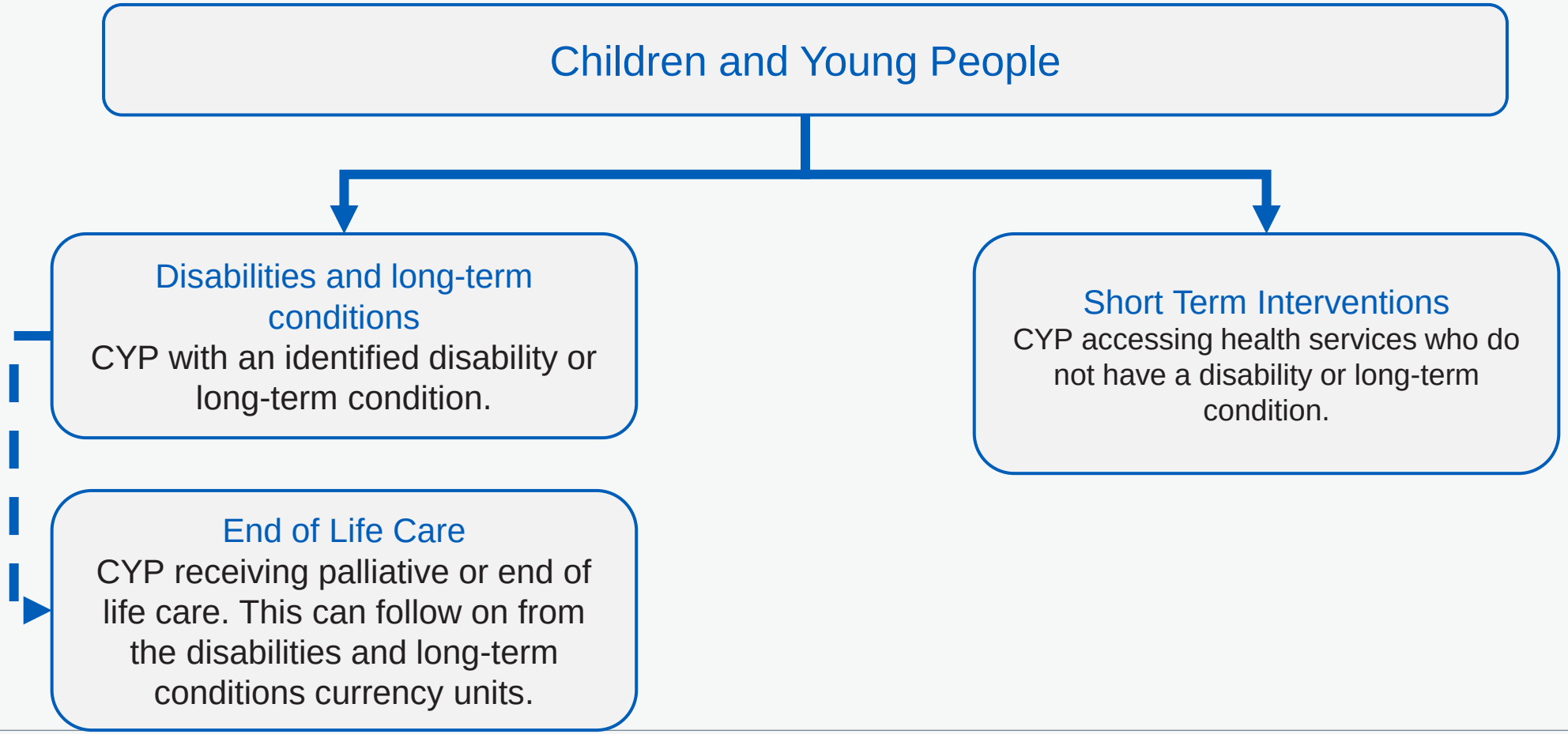
- Evidence has found that the needs of patients in the stable, unstable and deteriorating phases will vary based on functional status.
- Patients should be assessed regularly for PoI, with changes being recorded to understand these changes in need.

Currency Unit	Phase of Illness	AKPS Functional Status
LYOL_01	Stable	High
LYOL_02	Stable	Medium
LYOL_03	Stable	Low
LYOL_04	Unstable	High
LYOL_05	Unstable	Medium
LYOL_06	Unstable	Low
LYOL_07	Deteriorating	High
LYOL_08	Deteriorating	Medium
LYOL_09	Deteriorating	Low
LYOL_10	Dying	-
LYOL_11	Deceased	-

Children & Young People's Currency Model

Children and Young People's Currency Model

CYP currency development covers care provided in all settings, across the whole of England. There will be **three** streams to CYP currency development: CYP with Disabilities and Long-Term Conditions, CYP End of Life Support and Short-Term Interventions.



Next Steps

- Release of our soft launch models for 2024 – post-election
  - Dedicated NHS Futures Area
- Engagement on models and our future development through Summer
  - Thoughts on focus sessions for ICS, providers or sectors appreciated
- Further work on understanding value and quality
  - Any volunteers appreciated

Thank you.

For questions, please contact me at
Gary.Stinson@nhs.net

Q&A

HospiceUK

Feedback Survey

Please consider sparing a few minutes to answer this survey, so that we can continue to improve future Big Conversations events:

https://forms.office.com/e/3AHXNuxW95

Resources

- Contact our Clinical team: clinical@hospiceuk.org
- Outcomes, Data & Dashboards ECHO Network
  - 8 September 2024 from 15:30
  - Register to join: Join an ECHO - Outcomes, Data & Dashboards
- PCOM 360
  - Analysing Patient Centred Outcome Measures with PCOM360 | Hospice UK