Shared goals of care: national workshop summary

A workshop on developing a national approach to discussing and documenting shared goals of care with patients at high risk of dying during an admission to hospital was held at Te Papa, in Wellington, on October 26 2017. The purpose of the day was to explore current practice and identify clinical issues where work is needed. The findings of the workshop will inform further work which must involve consumers in identifying additional issues from their perspectives, and co-designing solutions that are fit for purpose.

An open invitation was extended to attend the workshop and ten district health boards (DHBs) were represented by participants on the day. These included approximately 50 senior and junior doctors, nurses, policy and quality leaders, and consumer advisors.

The morning sessions of the day were delivered by Health Safety & Quality Commission (the Commission) staff and invited speakers. These included background information about the patient deterioration programme, equity and consumer engagement in quality improvement work, and perspectives from a palliative care physician. Brief presentations from DHB representatives about their existing processes for discussing and documenting shared goals of care highlighted that there is significant current work underway. This ranges from the development of new forms for documenting limitations of medical treatment, to testing and implementing multi-disciplinary approaches to building shared goals of care discussions into usual practice. These sessions were filmed and are available on the Commission's website.

The afternoon sessions used a process called 'unconferencing' that allows participants to set the agenda. Participants pitched ideas, and topics were selected for discussion in small groups. The summaries of these conversations are in the appendix to this report.

Recurring issues identified in the discussions included the need for:

- training and education in the communication skills necessary for clinicians to discuss shared goals of care with patients, families and whānau
- standardisation of the principles underpinning shared goals of care discussions is more important than standardisation of a form for documentation of treatment limitations
- electronic access and alerts
- community education to improve health literacy and readiness for talking about death and dying
- consumer co-design of the tools, resources and framework for shared goals of care
- equity of access to timely shared goals of care discussions (for example, in the afterhours period)
- a cultural change in acute hospitals to improve multidisciplinary involvement in recognising patients at high risk of dying and planning for their care.

The Commission's next steps to further this work will include:

- discussion with the National Advance Care Planning Cooperative to consider opportunities to develop and/or align communication skills training for clinicians
- holding a hui and a national workshop with consumers to explore their perspectives about shared goals of care discussions and documentation.

Appendix: Summary of 'unconferencing' discussions

Topic: How to optimise consumer engagement

Our one big idea: **National co-design forum for goals of care. Nothing about me, without me.**

Main points of the conversation/emerging themes:

- Optimise early discussion
  - ACP
- "VOICES"
  - Family feedback on discussion
- Engagement must be culturally appropriate
  - Hui
  - Whakawhanaungatanga
  - Flexible to other cultures
- Must be authentic
- Feedback
  - After the fact, multi-modality
  - Liaise with 1° care

Ideas/questions/issues for further discussion:

- National framework
  - Systematic and consistent
  - Framework for training
- Funding
- Public engagement with design process
  - Social media

Topic: "It's not about the form" – So do we need a national one?

Our one big idea: **Standardised process – more important than the form**

Main points of the conversation/emerging themes:

- Measurable outcomes
- Drivers for consistency
- Changing culture
  - Parallel process
- Document as a Learning tool

Ideas/questions/issues for further discussion:

- GOC on discharge summary/communication to patient and HCP
- Does the form have to be the same regionally?
- How do you make the form work?
- Look at the lessons learned from such things as LCP. How can we mitigate this?
- Co-design with nurses

Topic: Training

- Nurses (all clinicians)
- RMOS
- How to have the conversation with a patient already deteriorating?

Our one big idea: Competency/skill to achieve to pass ACLS (life support) (Resus) certification (i.e. Demonstrate ability to have conversation about goals of care and wishes in relation to ACP / @ACLS training

Main points of the conversation/emerging themes:

- Depends on country of training
  - Not included in some medical training - Is it in New Zealand curriculum?
- Not included in orientation to medical practice in New Zealand (if there is an orientation) e.g. 1 day
- Who is influential to ensure this happens?
- Psychology of how we learn
- Key people to influence are New Zealand Resus Council
- Competency/skill to achieve to pass ACLS (life support) (Resus) certification (ie. Demonstrate ability to have conversation about goals of care and wishes in relation to ACP / @ACLS training

Ideas/questions/issues for further discussion:

- Registration bodies (medical/nursing council) to mandate
  - Need a national discussion
  - Make part of APC
- Responsibility for supervising medical/nursing staff to support new staff to gain skills, be supervised
- Debrief etc
- Need to influence intern supervisors
- How do we continue to support → role of colleges in training programmes?
- Coles Book of Medicine (produced by Medical Council)
  - Include a chapter on ACP/goals of care
- Online training available

Topic: Culture change in healthcare to enable goals of care conversations

Our one big idea: MAKING IT OKAY TO TALK ABOUT DYING

Main points of the conversation/emerging themes:

- Cultural change is huge and takes time
- Acceptance if dying, vulnerability and uncertainty
- Embedding of cultural change into high level strategy
  - MOH, DHB, operational strategy
- Equipping healthcare teams with tools
  - Patient, family, clinician stories

Ideas/questions/issues for further discussion: [None documented by group]

Topic: Patient/whānau health literacy about goals of care/death and dying

Our one big idea: Re-branding death and dying (no longer taboo subject)

Main points of the conversation/emerging themes:

- National Campaign about options for Care
- Integrate into other sectors i.e.
  - Education (start education early in age)
  - Legal sector
  - Community ownership
  - Social media
  - TV
- Realisation of effects of hospitalisation – time after/impacts
- Health literacy and awareness about Palliative Care – clarity around what it is

Ideas/questions/issues for further discussion:

- Cultural differences – acceptances/resistance to death/dying
- Piggyback on euthanasia conversation/debate
- Supported to die in place of choice
- Building compassionate communities/hubs of support

Topic: Measure GOC meet everyone's needs

Our one big idea: Should be measured

Data points include:

- **Percentage of patients have GOC**
- **Easily recognised GOC documents**
- **Patient/whānau understanding**
- **Satisfaction (e.g. competent conversation)**
- **Timelines – updated GOC conversations and changed**
- **Other opportunities for awareness and differences**

e.g. in ED waiting room – national campaign – interpreter used

Main points of the conversation/emerging themes:

- What do stakeholders expect to get from GOC
- Quantitative and qualitative measures e.g. info readily available – patients understood outcome of conversations
- Use layman's language for all conversation and documentation
- When in journey should this conversation happen e.g. pre-op

Ideas/questions/issues for further discussion:

- The GOC as determined by clinical team vs patient's GOC
- Cultural inputs
- Needs resourcing
- Where should GOC be started ED?
- National campaign to raise awareness on GOC conversations

Topic: Inequity of healthcare after hours?

Our one big idea: After hours care specific to hospital with adaptation of technology

Main points of the conversation/emerging themes:

- We should focus on getting more work done during day to avoid issues after hours
- It would be difficult and costly - resources
- Handover system:
  - People involved/plan
  - Identified by senior staff
- Using technology – teleconference.

Ideas/questions/issues for further discussion:

- After hours core model
- Adapting technology for afterhours care
- Changing culture to seek senior advice
- Looking at primary care involvement to plan for patients
- Audit

Topic: A national approach vs national forum

Our one big idea: "National implementation pathway" for shared goals of care in all acute hospital settings

Main points of the conversation/emerging themes:

- Standardisation
  - Standardise training
  - Public/consumer buy in
  - Audit of standardised measures
- Localisation is important
  - Culture
  - Regional service availability
  - Skill/resource availability
- Decision making follows patient with one patient one form. So i.e. "NMDHB form is legally binding in CCDHB".
- National framework to support implementation in smaller centres

Ideas/questions/issues for further discussion:

- Form ownership → DHB vs HQSC
  - Meeting predefined standards
  - Key components
- Logo and branding of form → national branding/regional form
- Paper and electronic options
- Guidance on ethical and legal framework and a la carte menu of forms suitable for different types of types of hospital patient info:
    - Highly structured (undeveloped service)
    - Less structured (advanced service)

Topic: Documentation/ one access point

Our one big idea: **National alert with attachments (updateable) GOC/ACP**

Date of creation and date of last update and where created and who.

Main points of the conversation/emerging themes:

- Electronic records
  - Access for all
  - Including patient held information (app)
  - How to access/most up to date version
- Revisiting GOC
  - Altering fixed discussions
  - Integrating MDT conversations
- When to start Advanced Care Planning? GOC?
- Part of National Alert System

Ideas/questions/issues for further discussion:

- Starting conversations by family well before hospital admit
- What should be included? Not included?
- Whiteboard icons (ACP)
- Electronic access for all (GP/hospital/ambulance/rest home)

Topic: Teach/ educate around GOC (in an inclusive way)

Our one big idea: **Communication skills:**

- **Core competence (mandatory)**
- **Supported education (ongoing)**
- **Become normal "culture" of practice**
- **For all (doctors, nurses etc)**

Main points of the conversation/emerging themes:

- Shared agreed common language and understanding – (concept)
- Inclusive
  - Facts (what to teach) (CORE base)
  - Skills (how to do it (CORE base) (as important as skills like how to perform an appendectomy)
- Culture change (how to be effective)
- Legal (patient rights/medical staff rights/law)

Ideas/questions/issues for further discussion:

- Developing terminology/language
- Should include the 18 year old getting their appendix out
- $$$! Cost
- When and how – at what level of training? Undergrad? Post-grad? All

Topic: Improve recognition and acknowledgement of the acutely dying patient

Our one big idea: Education and communication between medical, nursing and MDT

Main points of the conversation/emerging themes:

- Level of experience of doctors and RNs
- Barriers to escalate – hierarchy
- Access to services 24/7

Ideas/questions/issues for further discussion:

- Proactive documentation of what deterioration/dying would look like for a particular patient
- Team training especially for junior staff

Topic: Blurred lines/ I don't know

Our one big idea: Effective discussions will provide clarity!

Main points of the conversation/emerging themes:

- Right time, right place, right person → Review
- National campaign
- Living document (discussion)
- Honesty and humility

Ideas/questions/issues for further discussion:

- How do we do this?
- Communication resources/education
- Secondary/primary/everyone

Topic: Empowering all members of the MDT to have GOC conversations allowing patient to decide who they wish to speak to

Our one big idea: Aspiration: "The patient feels comfortable to discuss GOC with any member of the MDT. Their chosen person will be able to advocate for them"

GOC is discussed at MDT meetings for each patient. It becomes common language for all HCP.

Main points of the conversation/emerging themes:

- Timely conversations (for patient and team and trajectory)
- Recognising diversity and support networks
- Nursing role in GOC conversations
- GOC conversation is evolving and responsive and patient centric.

Ideas/questions/issues for further discussion:

- Legal and ethical issues
- Right info, right person at the right time
- Not a tick list, bang all conversation