

SPSP Paediatric Webinar

Worry and Concern: A Focus on Parental, Carer and Patient Concern

Wednesday, 5 June 2024

Chair's welcome



Dr Sonia JosephNational Clinical Lead for Paediatrics
Healthcare Improvement Scotland



Agenda



Time	Topic	Lead
12:30-12:35	Welcome and aims of the webinar	Dr Sonia Joseph, National Clinical Paediatric Lead, Healthcare Improvement Scotland
12:35-12:50	Current climate around worry and concern	Tim Shearman, Improvement Advisor, Healthcare Improvement Scotland
12:50-13:10	Kōrero Mai/Talk to me	Jess Hart, Clinical Nurse Consultant, Starship Child Health
13:10-13:25	Q&A	Dr Sonia Joseph
13:25-13:40	Safe transfer of care	Annie Campbell, Senior Paediatric Charge Nurse, NHS Lanarkshire
13:40-13:55	Q&A	Dr Sonia Joseph
13:55-14:00	Summary and next steps	Dr Sonia Joseph

Aims of the webinar



- To understand responses to worry and concern in paediatric services in the current context
- To explore patient, family and carer concern in relation to the work of the SPSP Paediatric Collaborative
- To share a range of examples of interventions which act on patient, family and carer concern



Current climate around worry and concern



Tim Shearman

Improvement Advisor
SPSP Paediatric Programme
Healthcare Improvement Scotland

Special thanks to: **Amy Wilson** and **Mark Wilson**, Physiotherapy Students, Queen Margaret University







SPSP Paediatric Programme timeline





Board visits and quarterly data submissions

2023 Deteriorating Child & Young Person Driver Diagram



What are we trying to achieve...

To reduce harm from deterioration by improving the recognition, response and review of the deteriorating child and young person**

By [locally agreed %] by 31st March 2025

*Essentials of Safe Care

**Measurements may include
existing Excellence in Care data

We need to ensure...

Person-centred care*

Recognition of acute deterioration

Standardised, structured response and review

Safe communication across care pathways*

Leadership to support a culture of safety at all levels*

Which requires...

Patients, families and carers are listened to and included
Person-centred care planning
Anticipatory care planning & CYPADM
Discussions with families are well managed

Observations using PEWS (Scotland)

Action on staff concern

Action on patient, family and carer concern

Timely review by appropriate decision maker
Assessment for causes of acute deterioration
Escalation
Regular review and assessment

Interdisciplinary teamwork and collaboration*
Use of standardised communication tools*
Effective communication in different situations*

Psychological safety for staff*

Staff wellbeing*

Safe Staffing*

System for learning*

Worry and concern



History

Research

Wider interest

Data

Voices of families



1. Boseley, S. Listen to parents of sick children rather than tests, NHS tells doctors [Internet]. The Guardian; 2016 [cited 2024 May 28]. Available from: Listen to parents of sick children rather than tests, NHS tells doctors | NHS | The Guardian

Voices of families



"They never really listened to us. I remember my husband saying to one doctor who came over: "she's just looking straight through us ... This is not my daughter" And he [the doctor] didn't take that seriously." Eleanor, Zoe's mum

Voices of families

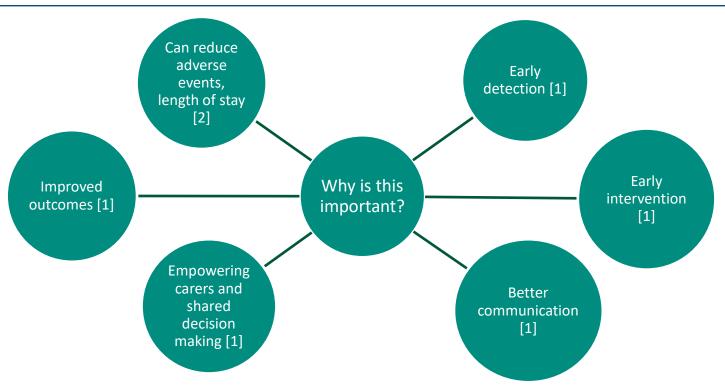




SPSP Deteriorating Patient and Sepsis Improvement Resources

Why is this important?





^{1.} Heath G, Montgomery H, Eyre C, Cummins C, Pattison H, Shaw R. Developing a tool to support communication of parental concerns when a child is in hospital. Healthcare. 2016 Jan 13;4(1):9. doi:10.3390/healthcare4010009

^{2.} Gill FJ, Cooper A, Falconer P, Stokes S, Leslie GD. Development of an evidence-based escalation system for recognition and response to paediatric clinical deterioration. Australian Critical Care. 2022 Nov;35(6):668–76. doi:10.1016/j.aucc.2021.09.004

Wider context



Martha's Rule – NHS England [1] 3 proposed components:

- All NHS staff have access to the 24/7 Rapid Review Team to raise concerns regarding a child's deterioration
- All patients, families and carers have access to the 24/7 Rapid Review Team to raise concerns regarding their child's deterioration
- 3. Structured approach to obtain information from patients/families daily



^{1.} Foster A. Martha's rule to be introduced in NHS hospitals from April [Internet]. BBC; 2024 [cited 2024 May 24]. Available from: https://www.england. NHS England» Martha's Rule [Internet]. www.england.nhs.uk. 2024. Available from: https://www.england.nhs.uk/patient-safety/marthas-rule/

Wider context



- Third Sector
 - Florence Nightingale Trust
 - Patients association

 NHS England Worry and Concern Collaborative

Cincinnati Children's Hospital [1]



Interventions – UK and Ireland



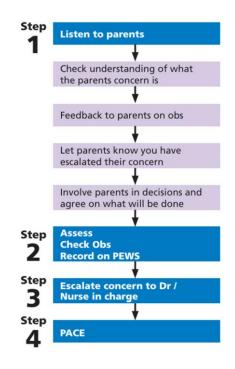
HSE – Republic of Ireland [1]

What to do next if you have concerns about your child

Step 1	You can: Talk to your nurse	
Step 2	We will: Assess your child and their vital signs Record the vital signs on the observation chart and work out their total PEWS score Talk to you about what we find Keep you informed and involve you in decisions	
Step 3	We will: Speak to the nurse in charge or your child's doctor if needed You can: Talk to a doctor on the ward round or ask the nurse to call your child's doctor	

1. Health Service Executive. Paediatric Early Warning System (PEWS) [Internet]. 2016 Nov. Available from: https://www.hse.ie/eng/about/who/cspd/ncps/paediatrics-neonatology/paediatric-early-warning-score/parent-information-4pp-a5.pdf 2. NHS England. Listening to you [Internet]. 2015. Available from: https://www.england.nhs.uk/patientsafety/wp-content/uploads/sites/32/2015/03/parents-leaflet2.pdf

Listening to you – NHS England [2]



Interventions – Australia



Calling for Help (C4H) - Western Australia [1]



1. Gill FJ, Leslie GD, Marshall AP. Parent escalation of care for the deteriorating child in hospital: A health-care improvement study. Health Expectations. 2019 Jul 16;22(5):1078–88. doi:10.1111/hex.12938

Ryan's Rule – Queensland [2]



^{2.} The State of Queensland: Ryan's rule [Internet]. The State of Queensland; Queensland; 2024 [cited 2024 May 20]. Available from: https://www.qld.gov.au/health/support/shared-decision-making/ryans-rule

Evidence



INTENS CRIT CARE NUR 75 (2023) 100



Review Article

Paediatric f systematic i

Shannon Creshal Joseph C. Mannin "Communication with patients and members of the clinical team is key to good clinical practice, providing our patients with world-class care and a safe environment for providing that care. Parents know their child best and their concerns should never be dismissed. The tragic case of Martha Mills highlights the importance of listening to parents in the context of inpatient deterioration. Listening to parents and children on first and subsequent encounters is key to a culture which provides patient safety."

 Prof Steve Turner, Consultant Paediatrician in NHS Grampian and President RCPCH



ery and Social Sciences, Building 18, Central Queensland University, Bruce Highway, Rockhampton, Q 4702, Australia

^b Ce Hospital and Health Service, Queensland Health, Canning Street, Rockhampton, Q 4700, Australia

arsing, Midwifery and Paramedicine, Building 104, Pell Centre, Ballarat, Vic 3350, Australia

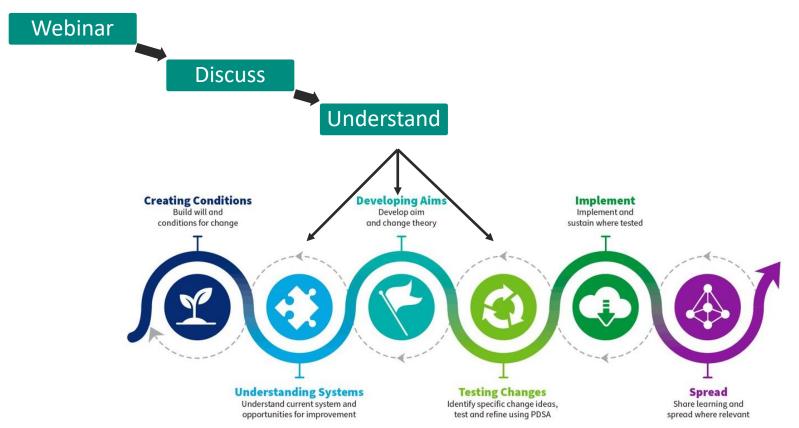
^a Nottingham Children's Hospital, No

^b Centre for Children and Young People I. United Kingdom

^c Library Services, Nottingham University Hospita

SPSP Paediatric Collaborative





Kōrero Mai/Talk to me



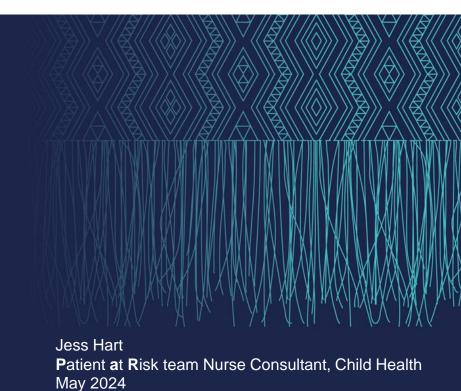
Jess Hart
Patient at Risk team Nurse
Consultant
Starship Child Health



Te Whatu Ora

Health New Zealand







Objectives

Share our work with you

Explain the project roll out

Describe how the pathway works

Update on service today

Health New Zealand, Te Whatu Ora

- 88 public hospitals in NZ
- 19 large tertiary
- 1 children's hospital (170 beds)

PaR, Child Health

- Under PICU
- Charge nurse, nurse educator, nurse consultant, SMO
- 14 nurse specialists



- > Northland (5)
- > Waitematā (6)
- > Auckland (6)
- > Counties Manukau (8)
- > Waikato (10)
- > Bay of Plenty (2)
- > Tairāwhiti (1)
- > Lakes (2)
- > Taranaki (2)
- > Whanganui (1)
- > Hawke's Bay (3)
- > MidCentral (3)
- > Wairarapa (1)
- > Hutt Valley (1)
- > Capital and Coast (5)
- > Nelson Marlborough (8)
- > West Coast (2)
- > Canterbury (14)
- > South Canterbury (1)
- > Southern (5)



Search

Q

Patient, family and whānau escalation

A guide to co-designing your Korero mai service

Project start-up

Engage stakeholders

Capture

Understand

Improve

Measure

Review

A guide to co-designing your Kōrero mai service

A guide to help hospitals implement Korero mai – an escalation process for patient, family and whānau concerns about deterioration while in hospital

Introduction Guide structure The guide's structure follows the stages of co-designing a Korero mai project. These stages generally follow on from each other but may sometimes overlap. For example, Körero mai project teams may be engaging with stakeholders while also capturing and understanding data. Stages of a Korero mai project: 1. Project start-up 2. Engage stakeholders 3. Capture: consumer experiences using different methods 4. Understand: emotions and touchpoints along the journey of care 5. Improve: work together to identify and prioritise what to improve 6. Measure: check to see if experience is improving 7. Review. This guide describes the approaches Korero mai project teams have used and what they have found. Links are given to examples of techniques and tools used.

Korero Mai Project Group

Project Sponsor from Senior Leadership team

Working Group:

- General Paeds SMO
- RMO
- Senior Nursing Nurse Consultant; Charge Nurse; RN (CED)
- Kaiatawhai (Māori liaison team)
- Social Work
- PaR Nurse Specialist
- Clinical Nurse Manager
- Simulation team

Whānau (family) experience

Worried and concerned

Family 1: 3 year old child on ward (Dec 2019)

- Unwell 4/7 Pneumonia + pleural effusion, English not first language
- On admission, Mother feels child is not himself; a little lethargic.
- Ward round next morning (with interpreter) Mother feels child is drowsy; surgical plan discussed; all questions answered.
- Post op Parents express concern to nurse that patient has stopped interacting with them
- 1700 Code Pink: Obtunded and tachypnoeic; responding to painful stimuli, post op drain insertion; PEWS 5. Later in evening, rousable, asking for food; drinking fluids. Reviewed by PaR and OCHS overnight; pain relief reviewed. Quiet but rousable.
- Next day Mother notices rash on legs; worried about drug reaction.
 OCHS review Mother concerned that child has not moved their right arm or leg since the operation; has been non verbal since yesterday.
 Child reviewed by Reg; Code Pink; seizure; Ct scan; Cerebral infarct; transferred to PICU for ongoing care

Family 2: 10 day old baby on ward (July 2019)

Dad expressed concerns at 1900 on ward; reviewed by OCHO

- · Sometimes has 5 minute periods of distress; desats accompanied by twitching
- Worried as family was reassured during pregnancy that everything was normal but then it wasn't (Baby born with high output cardiac failure due to an hepatic Arteriovenous malformation)
- Plan: Continue close observation; plan to do an EEG at some point
 Further review at o600 as febrile and more abnormal movements OCHS + PaR
- Parents report abnormal movements every 20-30 minutes all night; Father very
 upset, reported baby had been doing this all night and no one had listened. Video
 taken; baby had not been feeding since early evening, lip smacking.
- Plan: Anticonvulsants; Hypocalcaemic seizures; transferred to PICU for IV Calcium infusion
- In PICU, Parents distressed, verbalising that they feel that their concerns about their baby have not been acted on; that they were not listened to and staff were too busy. Father feels the care offered was not satisfactory. Supported by social worker in PICU; declined CLT.

Family 3: 1 year old on ward (Oct 2018)

- Mother reports child had an episode of unresponsiveness, fluffy and cyanotic in colour.
 Mother concerned heart rate high. Mum rang call bell, nurse review, child alert, vital signs normal. (JMML; 4/12 Post BMT, PHTN; discharge planning for home)
- 40 minutes later, Mother rings emergency bell; child blue, floppy and unresponsive. Code Blue – transferred to PICU for cardiac monitoring.



Family 4: 2 year old child on ward (Sept 2018)

- Post T's and A's; Gastrostomy insertion; ex 31/40; extensive cardiac history; pacemaker insitu; several admissions to PICU for hypoxia.
- Night shift: Dad expresses concern to nurse that pacemaker may not be working properly; low HR on pleth; unable to record BP; unsettled night - diarrhoea; desaturating at times on HFNC
- Pacemaker checked next day ok; Dad still concerned about pacemaker
- Next day; Father rang call bell at 0900 worried child more lethargic. Nurse notified PaR NS who was on the ward; Father rang emergency bell; Code Blue; child mottled and no pulse present; PEA arrest; child was not able to be resuscitated

COVID 2020 accelerated things

Kōrero Mai Project

- Project scope SSH wards
- Mokopuna and whānau engagement
- 0800 number
- Bedside posters
- Information resources for mokopuna and whānau
- Linked in with Starship Speak Out For Safety and Medical Mediation programmes



Speak Out for Safety

Graded assertiveness tool to assist staff to escalate concerns





Escalation pathway for whānau and kaimahi

Whānau (family)

3 steps:

- 1. Talk to your nurse
- 2. Talk to the Nurse in Charge

3. Talk to the Code Pink (RRT) team

Kaimahi (staff)

At each step the staff member will:

- acknowledge and explore the young person, parent, or whānau concern
- assess and review the child's condition
- escalate care to RMO/SMO and senior nursing staff
- share decision-making with young person, parent or whānau
- check back with young person, parent or whānau that concern is resolved and they or their child is physiologically stable



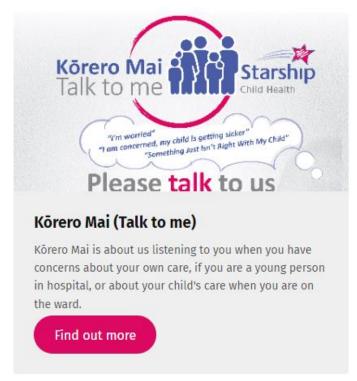
Kōrero Mai poster

These spaces are completed to provide the caller with a script

Korero Mai whānau information



Starship Clinical Guidelines Patient, Parent or Visitor



Starship website:

Patient, parent or visitor tile → Kōrero Mai →video



Coming to Starship Hospital

Information for visitors

Preparing for your hospital stay

Staying with your child

Activities for your child

Places to eat Going home



Coming to an Outpatient Appointment

Information about what to expect when you bring your child to an Outpatient Appointment

Find out more



When your baby is in NICU

See all

Information for parents who have a baby in the Neonatal Intensive Care Unit at Starship



Health information

Information for whānau, tamariki and rangatahi on child health topics





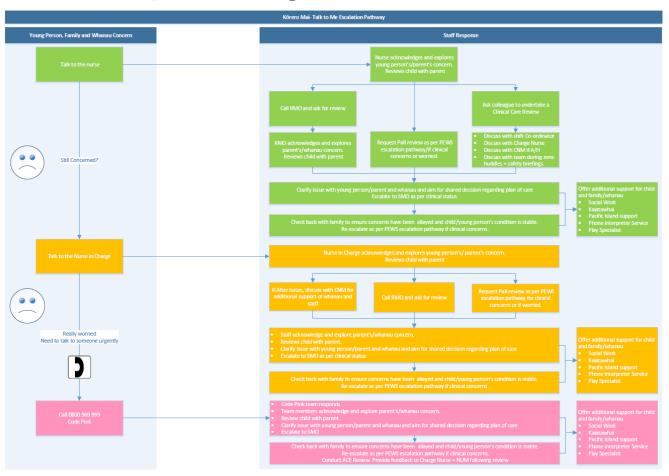
Kōrero Mai (Talk to me)

Körero Mai is about us listening to you when you have concerns about your own care, if you are a young person in hospital, or about your child's care when you are on the ward.

Find out more

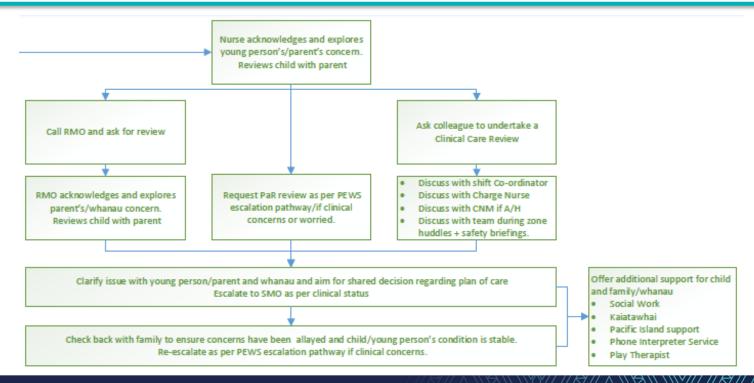


Escalation pathway for whānau and kaimahi



Step 1 Talk to the nurse

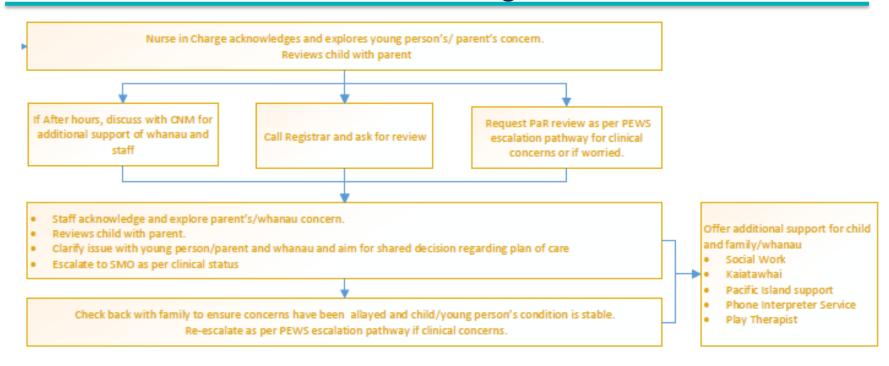




Step 2

Ask to talk to the nurse in charge





Step 3Call 0800 969 999 - Code Pink





- Code Pink team responds
- Team members acknowledge and explore parent's/whanau concern.
- Review child with parent.
- . Clarify issue with young person/parent and whanau and aim for shared decision regarding plan of care
- Escalate to SMO

Check back with family to ensure concerns have been allayed and child/young person's condition is stable.

Re-escalate as per PEWS escalation pathway if clinical concerns.

Conduct ACE Review. Provide feedback to Charge Nurse + NUM following review

Offer additional support for child and family/whanau

- Social Work
- Kaiatawhai
- Pacific Island support
- Phone Interpreter Service
- Play Therapist

Te Whatu Ora

Health New Zealand

What worked well

- Senior leadership influence
- MDT perspectives voice of Social Worker and Kaiatawhai to understand vulnerability of whānau and their ability to feel safe to speak out when concerned
- Whānau engagement development of resources
- Dedicated time to commit to project nursing + sim team
- Highly motivated team to lead education sessions clinical and non clinial staff
- Involvement of PaR NS and CNM and RMO 24/7 team, after hours support
- Time spent on Korero Mai calls is similar to time spent on other code pink calls (45-60min)

Kōrero Mai now

- Low numbers of Korero Mai code pink calls
- Steps 1 & 2 are invisible to PaR
- PaR database captures high rates of parental concern as a reason for review
- Large turn over of staff post Covid
- How imbedded is the service?

PDSA

- Information gathering....
- Explore Korero Mai now with other hospitals in Auckland
- Interview nurses and parents
- Poster audit
- Identify knowledge gaps
- Explore redesigning the resources
- Target education to where it is needed
- Roll out Korero Mai in ED
- PICU next?

Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?



Busting myths

Korero Mai is for parents who want to complain

Korero Mai is about miscommunication

Tell them about Korero Mai on admission only

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Temperature	2-	95		×					.1																	≥ 40		1			
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write value if off scal	5												-		X.	1		-	ă.		1	P	*	*	12,4	36s					
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write score (0-10)	Marrie			0	19%	9	0	0	00	/	00	1	00				00	96	00	0	00	0	02	80	6 %	Rest	Reason:				



Ngā mihi

(thank you)

Questions?

Safe Transfer of Care



Annie Campbell
Senior Paediatric Charge Nurse
NHS Lanarkshire



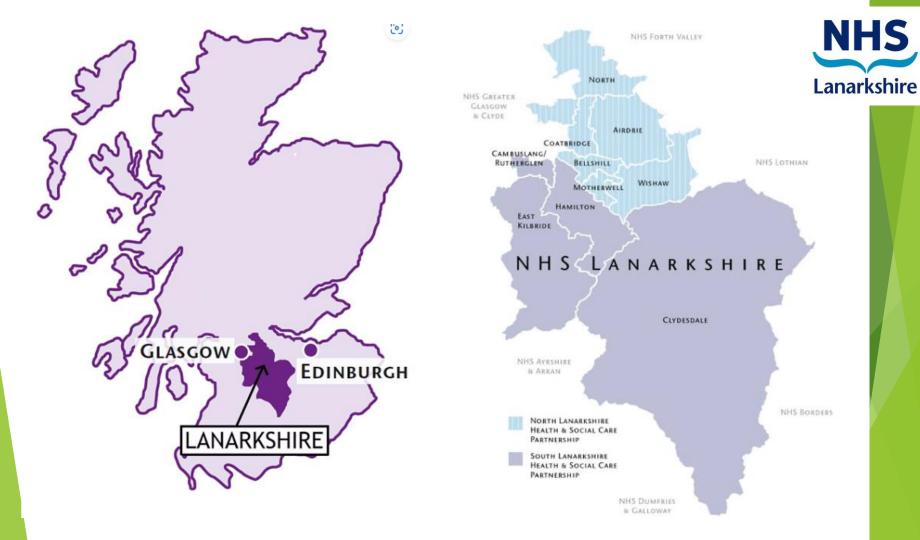


Safe Transfer of Care

University Hospital Wishaw Ward 19 & Ward 20



- Background and context
- Aim
- Change Ideas
- Next Steps



NHS Lanarkshire



- Population total 664,030
- ▶ 132,243 under 16 (approx. 10% of population)
- Lanarkshire predominately industrial area/rural and urban areas
- ► Furthest point of referral up to 60 miles away
- Covers areas of high deprivation/poverty
- 3 hospital sites
- 1 site for paediatrics
- Referrals 3 ED sites, GP, HV, out of hours service, open access and 48hr open access

Paediatric Wards 19 and 20, University Hospital Wishaw

NHS Lanarkshire

<u>W20</u>

- 24 inpatient beds
- specialities covering Medical, Surgical, Orthopaedic, ENT, Mental Health
- 2,757 patients admitted for treatment last year
- 1 SCN, 4 Band 6, 20 Band 5 staff nurses, 6 Clinical Support Workers

<u>W19</u>

- 16 assessment beds
- Day clinic biologic infusions, bloods, investigations, botox, day surgery,
- Medical reviews
- 7,238 patients seen for assessment last year
- 4,045 day patients last year
- 1 SCN, 3 Band 6, 20 Band 5 staff nurses, 6 Clinical Support Workers



Aim

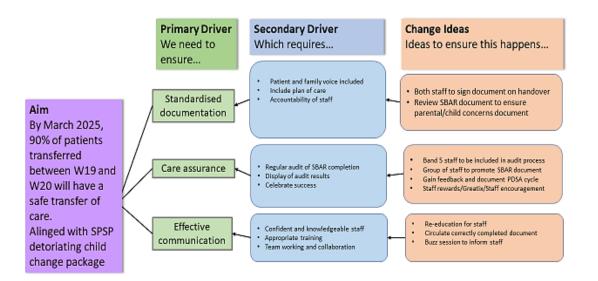


Locally we have focused on the area of safe patient transfer and our aim is:

"90 % of children will experience a safe transfer of care between paediatric wards 19 and ward 20, UHW by March 2025."

Aligned with SPSP deteriorating child change package.





Change Ideas

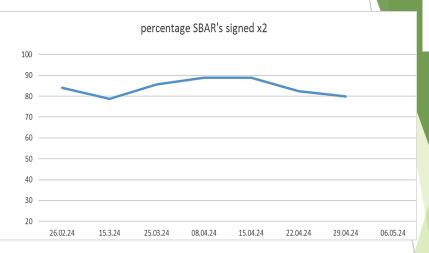
NHS Lanarkshire

- ► Review SBAR transfer document
- ▶ Ward display
- ► Buzz sessions
- ► Staff champions
- ► Promote care opinion

Paediatric Internal SBAR Transfer (Trial 2)

t name Sex: DM DF dress	Next of kin details recorded? Next of Kin informed of transfer?	Yes	□ No
	Any Parental Concerns? If yes, specify:	Yes	No
se entro addresspope habet here e- Handover Checklist: Band On	Handover Checklist: ID Band On E-Care completed Sepsis 6 completed Height/Weight Kardex completed inc C Recent PEWS PVC Bundle Fluid Balance PYMS		34
in Score Working Diagnosis:	Pain Score	-	
PEWS score: at: :	33	egular Meds:	
Medical History:			
Allergies:			
	Interventions; Treatment Given; O2 commenced Prescribed NGT insitu SizeFr Taped at		
Red name band Investigations carried out: Point of care test (POCT): Pos/Neg Urine dip Bloods Bloods	Treatment Given: O2 commenced Prescribed NGT insitu SizeFr		





- Trial of SBAR document
- Changes to placement of signature
- Addition of checklist
- Identified parental concerns captured but no documentation of action taken



Next of kin details informed of	Yes	☐ No
transfer		
Next of Kin updated to plan of	Yes	☐ No
care?		
Any Parental Concerns?	Yes	☐ No
If yes, documented?		
Reassurance given?		

Welcome to Ward 20

Children's in-patient ward

University Hospital Wishaw



- We are currently gathering feedback on our Patient's Parents/Guardians
 experience of being transferred from Ward 19 (triage) to Ward 20 (in-patient
 ward), the purpose of this is to identify any areas for improvement and to ensure
 everyone has a positive experience.
- We ask that you complete a short survey, it takes less than two minutes and is completely anonymous.
- Information gathered will be viewed only by Ward Management and is stored securely via NHSL R-drive.
- Please find the survey by following this link:

https://forms.office.com/e/Cr9rR5jX9f?origin=lprLink or

Scanning the following QR code:



* Required
Were you informed of the plan of care for your child? *
Yes
○ No
Could have been better
2. How would you rate your experience of transfer between the triage ward and the in-patient ward? *
3. If you had any concerns/questions, do you feel these have been addressed or have they been escalated? *
○ Yes
○ No
Submit Never give out your password. Report abuse









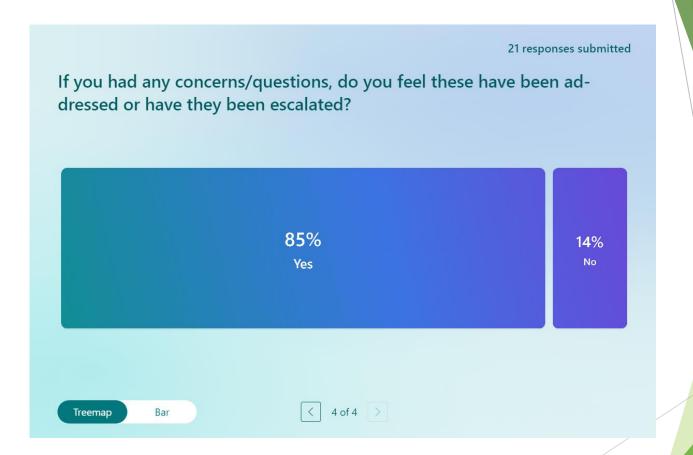
21 responses submitted

If you chose ' No' or 'Could have been better' - what do you feel could have been done differently to improve your experience?

"We had been in ward 19 since 4pm and never came through to ward 20 until 330am and couldn't turn off lights or dim them for my son to go to sleep in ward 19 had to sit on an iPad until 3:30am which is not good as he is on the spectrum

"Explain more why we are in ward 19"

"I didn't take in much at the time as I was so worried about her. "





Next steps



- SCN completed daily walk-round, speaking to parents
- ► The less than positive feedback communication, introduction to new staff, what plan of care was
- Review feedback and explore any themes
- Continue to promote safe transfer and explore how we can escalate parental concern
- ▶ Parent/Patient focus group

Stay in touch





- Contact us at his.spsppp@nhs.scot
- Subscribe to the <u>SPSP Paediatric mailing list</u>
- Visit the <u>SPSP Paediatric Programme website</u>
- Visit the <u>Essentials of Safe Care website</u>



https://forms.office.com/e/uZyBnxygPy