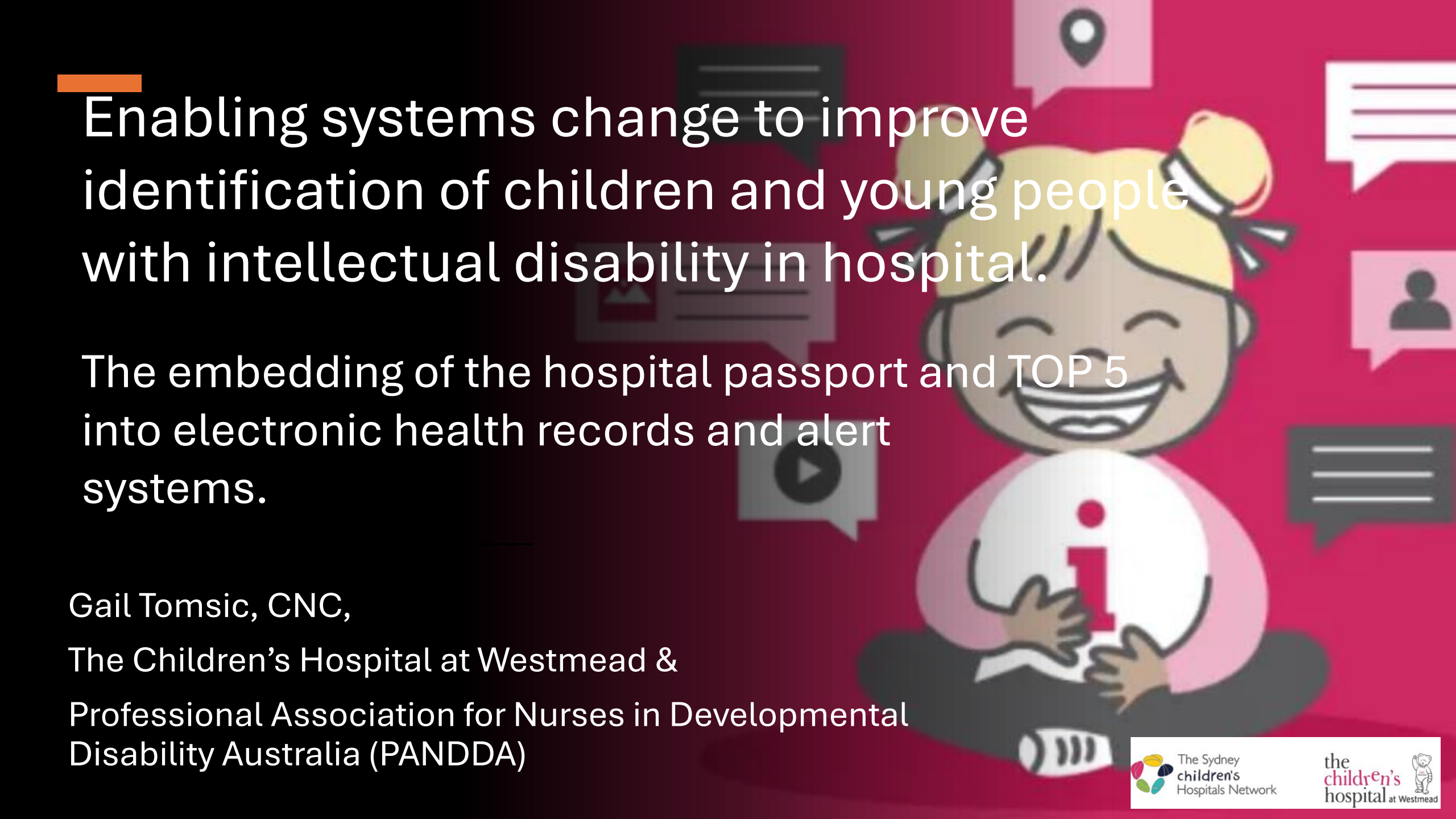
# Enabling systems change to improve identification of children and young people with intellectual disability in hospital.

## The embedding of the hospital passport and TOP 5 into electronic health records and alert systems.



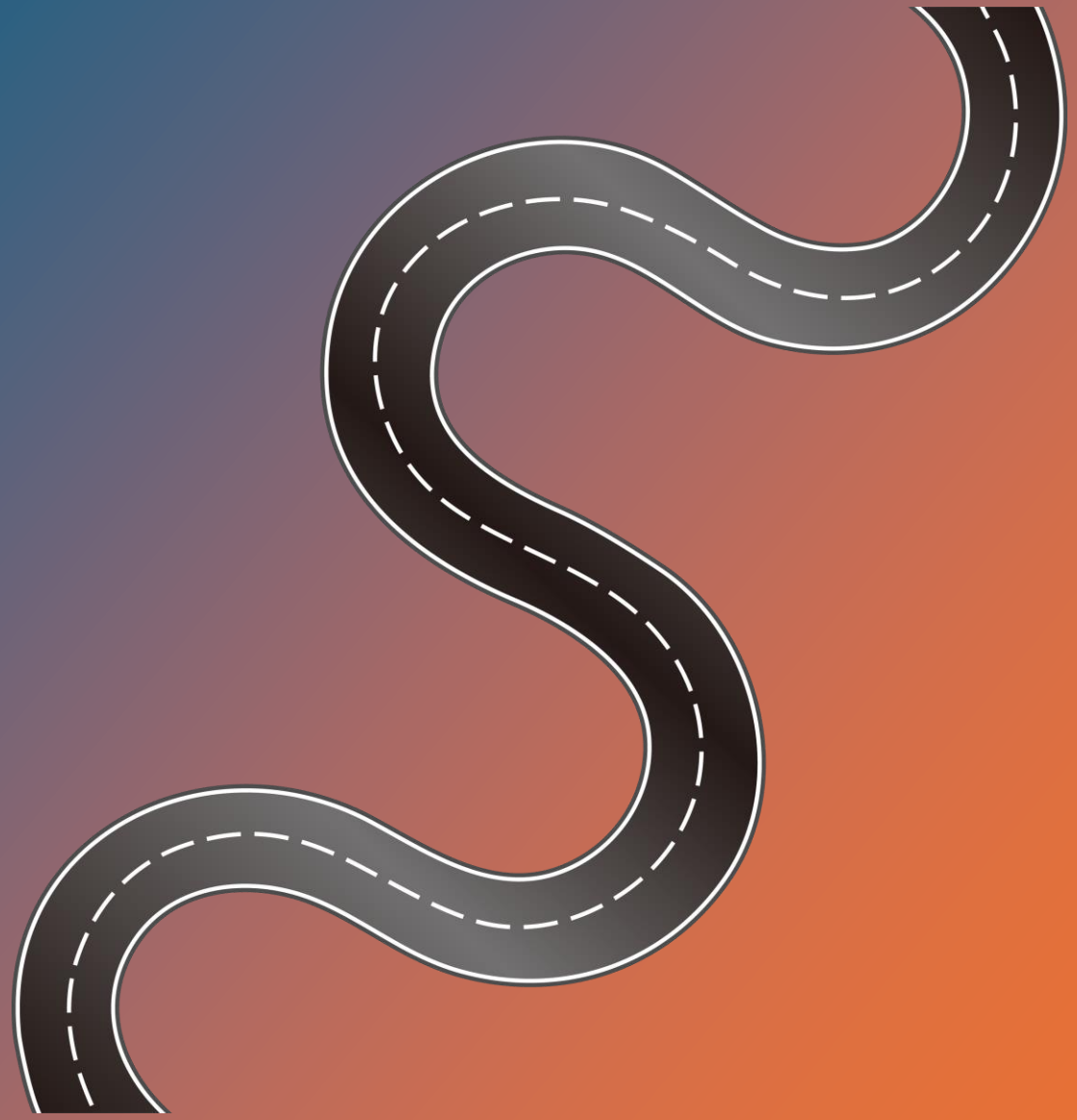
Gail Tomsic, CNC,

The Children's Hospital at Westmead &

Professional Association for Nurses in Developmental Disability Australia (PANDDA)

The Sydney Children's Hospitals Network

the children's hospital at Westmead



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# Overview

- About the Tile
- How it evolved
- What we have found
- The Future

# Roadblocks to better care

Flagging

Increase
Adverse events

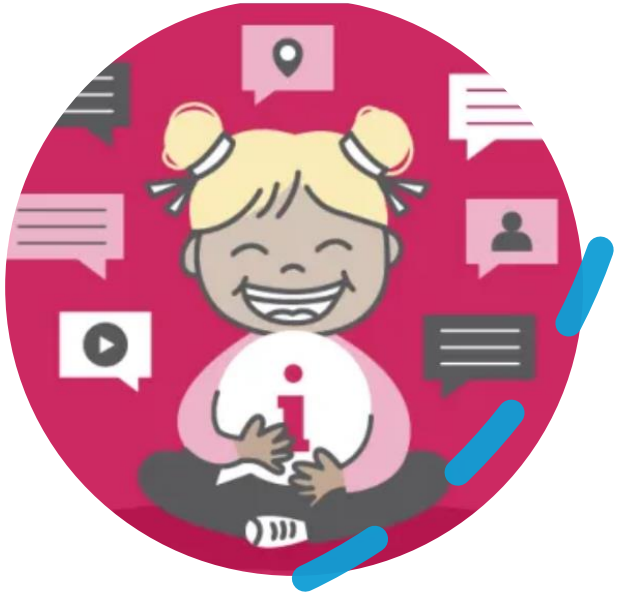
No information

Poorer Health
Outcomes

Longer Length
of stay

# The TOP 5 initiative

- **What it is**: A tool to collect crucial information from the person's carer to help healthcare staff understand their specific needs.
- **Who it's for**: Individuals with intellectual disabilities, dementia, autism, or other chronic health issues that make communication difficult.
- **How it helps**: It addresses communication and behavior challenges, supports patient comfort, and promotes continuity of care across different settings.
- **The process**:
  - A carer is asked to identify up to five essential care strategies.
  - These "TOP 5" tips are recorded on a form and added to the patient's medical notes.
  - This information is then accessible to all staff who interact with the patient, ensuring everyone is on the same page.



# Why the “Top 5” Matters in Hospital Care

1. **Supports communication**
   - Practical tips from carers prevent misunderstandings.
2. **Reduces anxiety and distress**
   - Knowing what comforts or upsets the person helps maintain calm.
3. **Promotes consistent care across staff**
   - Quick reference ensures all staff know key needs, even across shifts.
4. **Improves safety and quality of care**
   - Knowledge about medications, mobility, and eating prevents incidents.
5. **Values family and carer expertise**
   - Fosters collaboration and person-centred care.

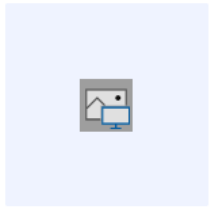
# How the tile was created

- Central Coast LHD
- 2013- 2014  Specialist Disability Team and ADHC Pilot Prototype
- 2015 used a paper version
- 2018 Digital form
- 2020 Used in COVID
- Presented to Clinical Governance Aug 2022
- PEACH- 2023
- Motivated for Change ED
- Nov 2023 EMR rollout
- The Build- Refinements pilot use from ED
- Translation to adult healthcare setting- My ED project

# Paper form

**My Name is:** *Child's name*

This is me



And these things are the important things to know about me.....

1. *Click here to enter text.*
2. *Click here to enter text.*
3. *Click here to enter text.*
4. *Click here to enter text.*
5. *Click here to enter text.*

**Please read the rest of my personal profile for more information about me and how to best support me.**



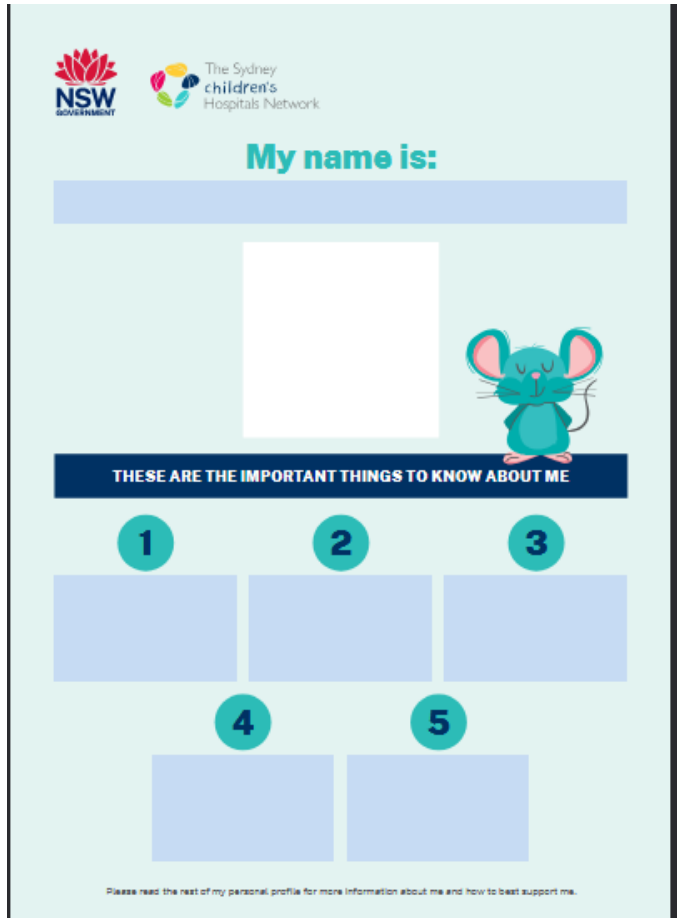
| Information about me | |
|---|---|
| **Date of Birth** | Click here to enter text. |
| **Medicare No.** | Click here to enter text. |
| **Address & Phone number** | Click here to enter text. |
| **Main contact people** | Main Carer: Click here to enter text.<br>Key Worker: Click here to enter text.<br>Person responsible/DCJ manager: Click here to enter text.<br>Who to contact in emergency: Click here to enter text.<br>GP: Click here to enter text.<br>Other therapists: Click here to enter text. |
| **Religion and cultural requests:** | ☐Aboriginal<br>☐Torres Strait Islander<br>Religion: Click here to enter text.<br>Ethnicity: Click here to enter text.<br>Language: Click here to enter text. |
| **ALLERGIES** | Click here to enter text. |
| **Current medications:** | Please include name, dose and frequency of use.<br>Click here to enter text. |
| **Current medical conditions:** | ☐ Epilepsy ☐Diabetes<br>☐Gastrointestinal disorder problems ☐Breathing<br>☐Diabetes ☐Heart Condition<br>☐OTHER: Click here to enter text. |
| **Current treatment plan:** | Please include any medical treatment plans:<br>Click here to enter text. |

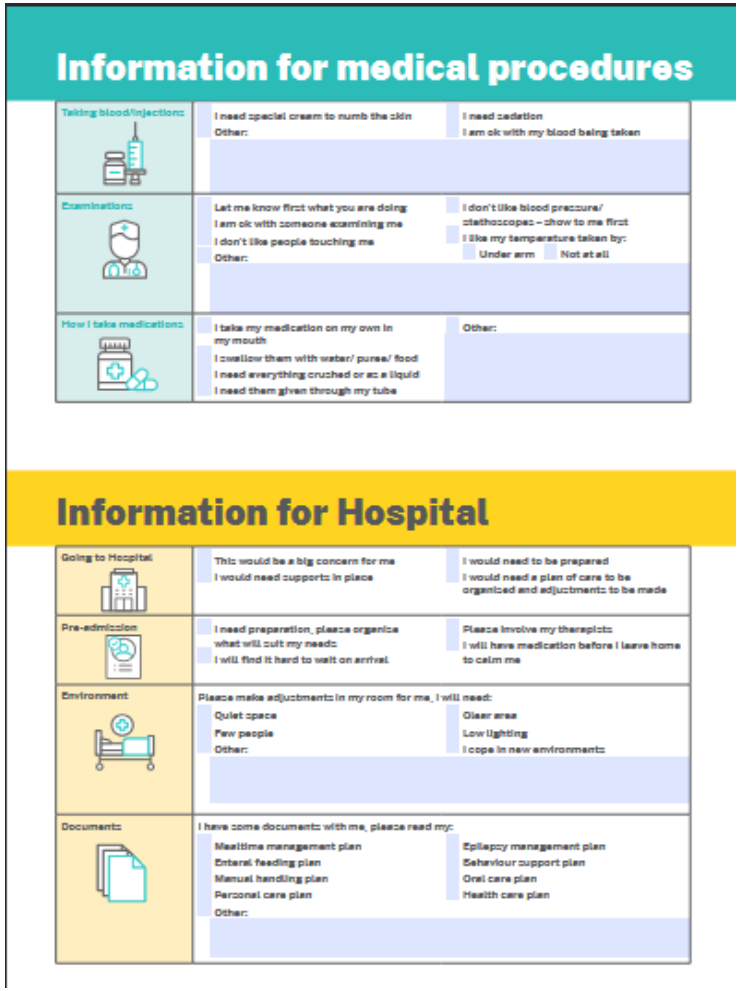


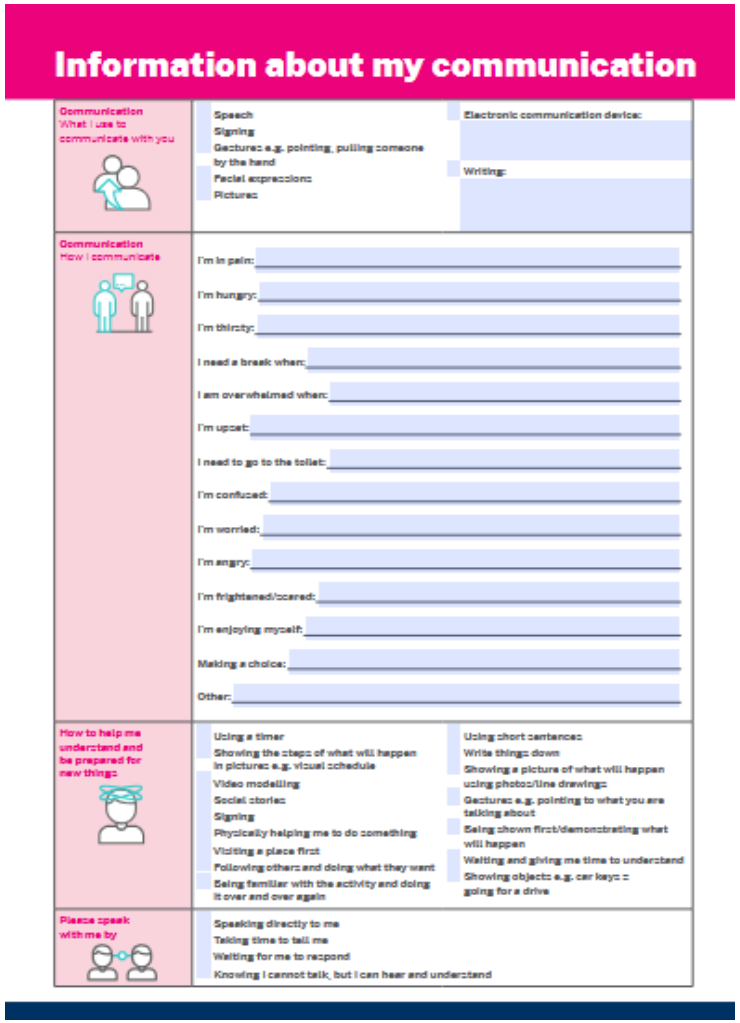
| | |
|---|---|
| **Blood Group (If Known)** | ☐A positive or negative<br>☐B positive or negative<br>☐AB positive or negative<br>☐O positive or negative<br>☐Unsure |
| **Consent For Medical Procedures**<br>**I...** | ☐ Understand most concepts and am able to consent<br>☐ Understand most concepts but am not able to consent<br>☐ Need parents/carers to consent on my behalf<br>Name of person consenting on my behalf:<br>Click here to enter text. |

| Information for Medical Procedures | |
|---|---|
| **Taking Blood/ injections** | ☐I need special cream to numb the skin<br>☐I need sedation<br>☐I am ok with my blood being taken<br>Other:<br>Click here to enter text. |
| **Examinations** | ☐Let me know first what you are doing<br>☐I am ok with someone examining me<br>☐I don't like people touching me<br>☐I don't like blood pressure/ stethoscopes– show to me first<br>I like my temperature taken by:<br>• Under arm ☐<br>• Not at all ☐<br>Other: Click here to enter text. |
| **How I take my medications** | ☐I take my medication on my own in my mouth<br>☐I swallow them with water/ puree/ food<br>☐I need everything crushed or as a liquid<br>☐I need them given through my tube<br>**Other:** Click here to enter text. |

# Hospital Passport




Hospital Passport

# New Top 5 Form

| | | | |
|---|---|---|---|
| Name | | | |
| MRN | | Date of birth | |
| Age | | Date completed | |

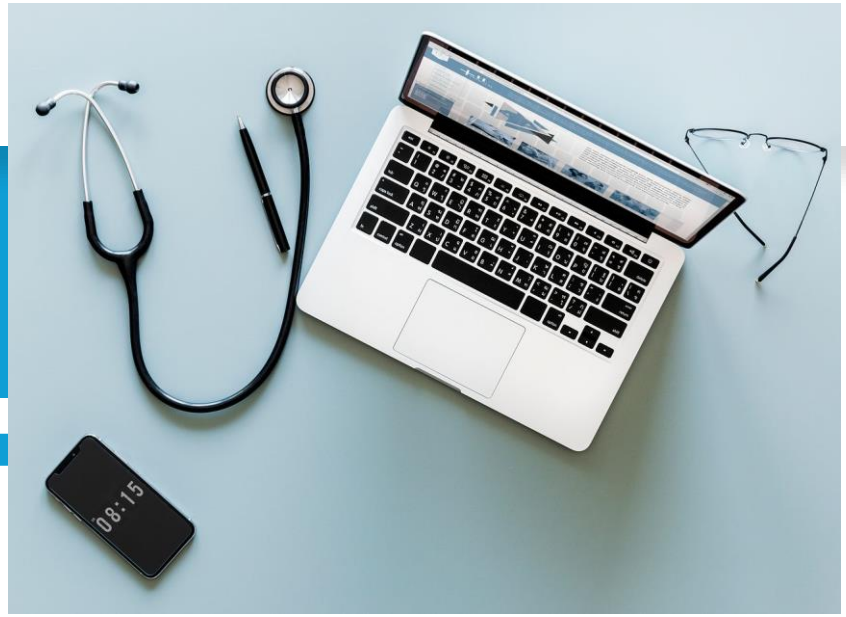
**These are the Top 5 things that are important to know about me:**

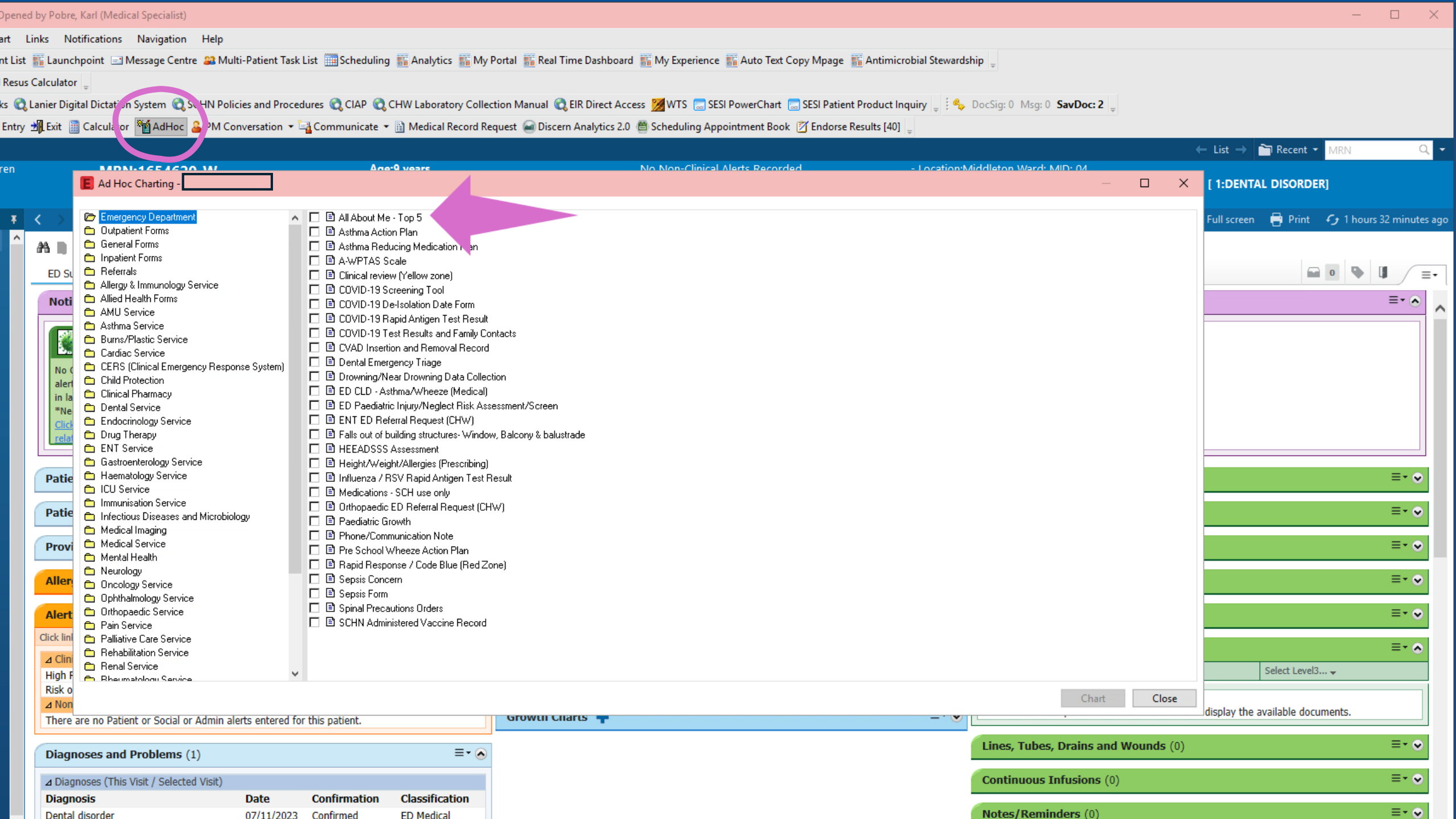
| | |
|---|---|
| 1. How do I communicate? | |
| 2. What are my likes and dislikes? | |
| 3. How do you know when I'm escalating and getting upset? | |
| 4. What calms me down? | |
| 5. Any other useful information eg, about me, how I go with procedures, need for sedation, environmental changes etc | |

DRAFT

CDU6189/0325

# So, how does this translate into a Electronic Medical Record?




Opened by Pobre, Karl (Medical Specialist)
Links
Notifications
Navigation
Help
Launchpoint
Message Centre
Multi-Patient Task List
Scheduling
Analytics
My Portal
Real Time Dashboard
My Experience
Auto Text Copy Mpage
Antimicrobial Stewardship
Resus Calculator
Lanier Digital Dictation System
CIAP
CHW Laboratory Collection Manual
EIR Direct Access
WTS
SESI PowerChart
SESI Patient Product Inquiry
SavDoc: 2
Exit
AdHoc
Communicate
Medical Record Request
Discern Analytics 2.0
Scheduling Appointment Book
Endorse Results [40]
List
Recent
MRN
Ad Hoc Charting -
Emergency Department
Outpatient Forms
General Forms
Inpatient Forms
Referrals
Allergy & Immunology Service
Allied Health Forms
AMU Service
Asthma Service
Burns/Plastic Service
Cardiac Service
CERS (Clinical Emergency Response System)
Child Protection
Clinical Pharmacy
Dental Service
Endocrinology Service
Drug Therapy
ENT Service
Gastroenterology Service
Haematology Service
ICU Service
Immunisation Service
Infectious Diseases and Microbiology
Medical Imaging
Medical Service
Mental Health
Neurology
Oncology Service
Ophthalmology Service
Orthopaedic Service
Pain Service
Palliative Care Service
Rehabilitation Service
Renal Service
All About Me - Top 5
Asthma Action Plan
A-WPTAS Scale
Clinical review (Yellow zone)
COVID-19 Screening Tool
COVID-19 De-Isolation Date Form
COVID-19 Rapid Antigen Test Result
COVID-19 Test Results and Family Contacts
CVAD Insertion and Removal Record
Dental Emergency Triage
Drowning/Near Drowning Data Collection
ED CLD - Asthma/Wheeze (Medical)
ED Paediatric Injury/Neglect Risk Assessment/Screen
ENT ED Referral Request (CHW)
Falls out of building structures- Window, Balcony & balustrade
HEEADSSS Assessment
Height/Weight/Allergies (Prescribing)
Influenza / RSV Rapid Antigen Test Result
Medications - SCH use only
Orthopaedic ED Referral Request (CHW)
Paediatric Growth
Phone/Communication Note
Pre School Wheeze Action Plan
Rapid Response / Code Blue (Red Zone)
Sepsis Concern
Sepsis Form
Spinal Precautions Orders
SCHN Administered Vaccine Record
Chart
Close
[ 1:DENTAL DISORDER]
Full screen
Print
1 hours 32 minutes ago
There are no Patient or Social or Admin alerts entered for this patient.
Growth Charts
Diagnoses and Problems (1)
Diagnoses (This Visit / Selected Visit)
Diagnosis
Date
Confirmation
Classification
Dental disorder
07/11/2023
Confirmed
ED Medical
Lines, Tubes, Drains and Wounds (0)
Continuous Infusions (0)
Notes/Reminders (0)

# Top 5 now with prompts

## All About Me - Top 5 Tips for Support

Last Updated Aug 2023

**Interpreter:** No **MC:** 26559705552
**LOC:** Emergency Cubes; ATA; 08
er Aboriginal nor Torres Strait Islander origin

These are the Top 5 things that are important to know about me:

Max 255 characters per field

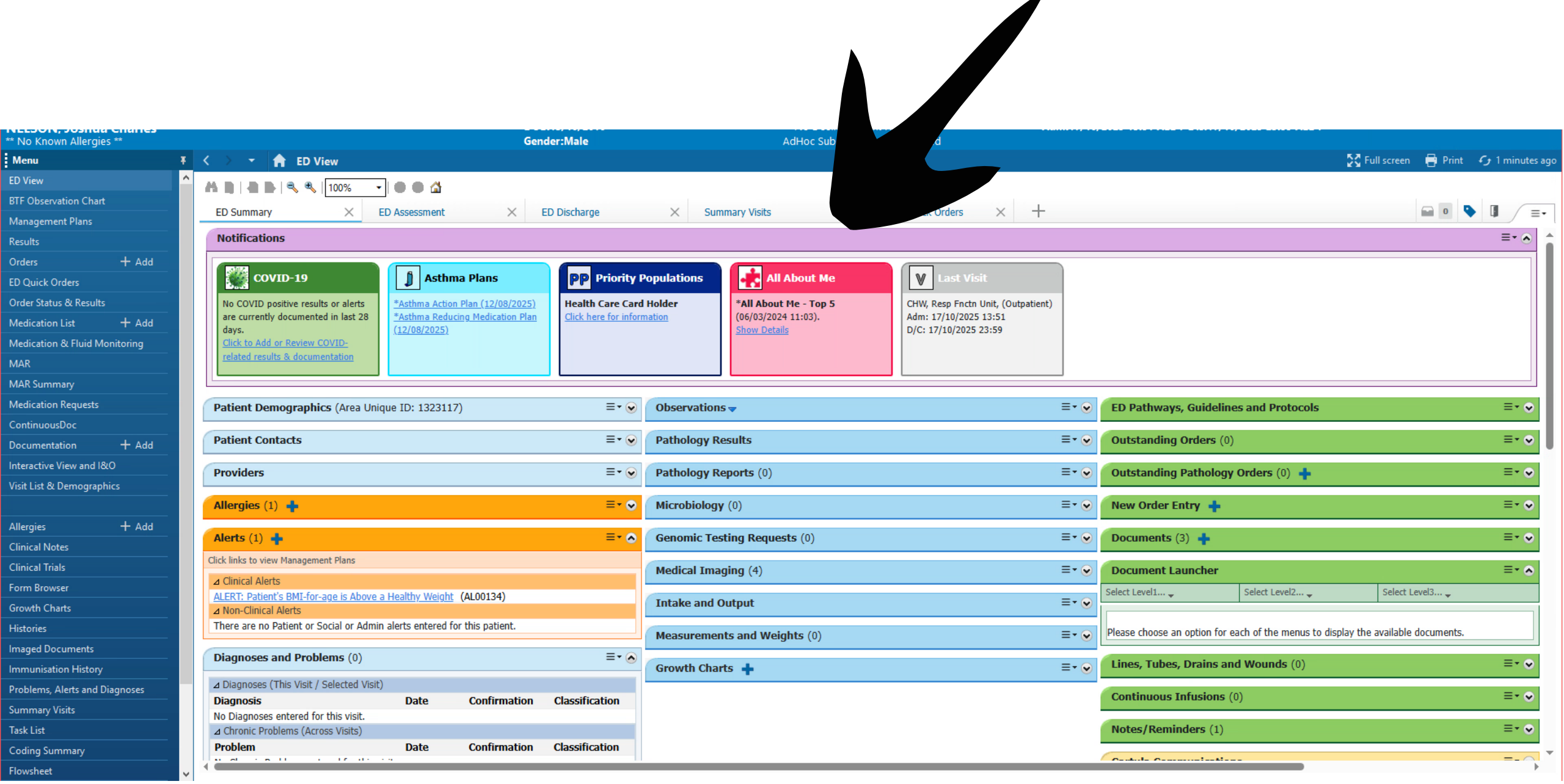
1. How do I communicate?

2. What are my likes and dislikes?

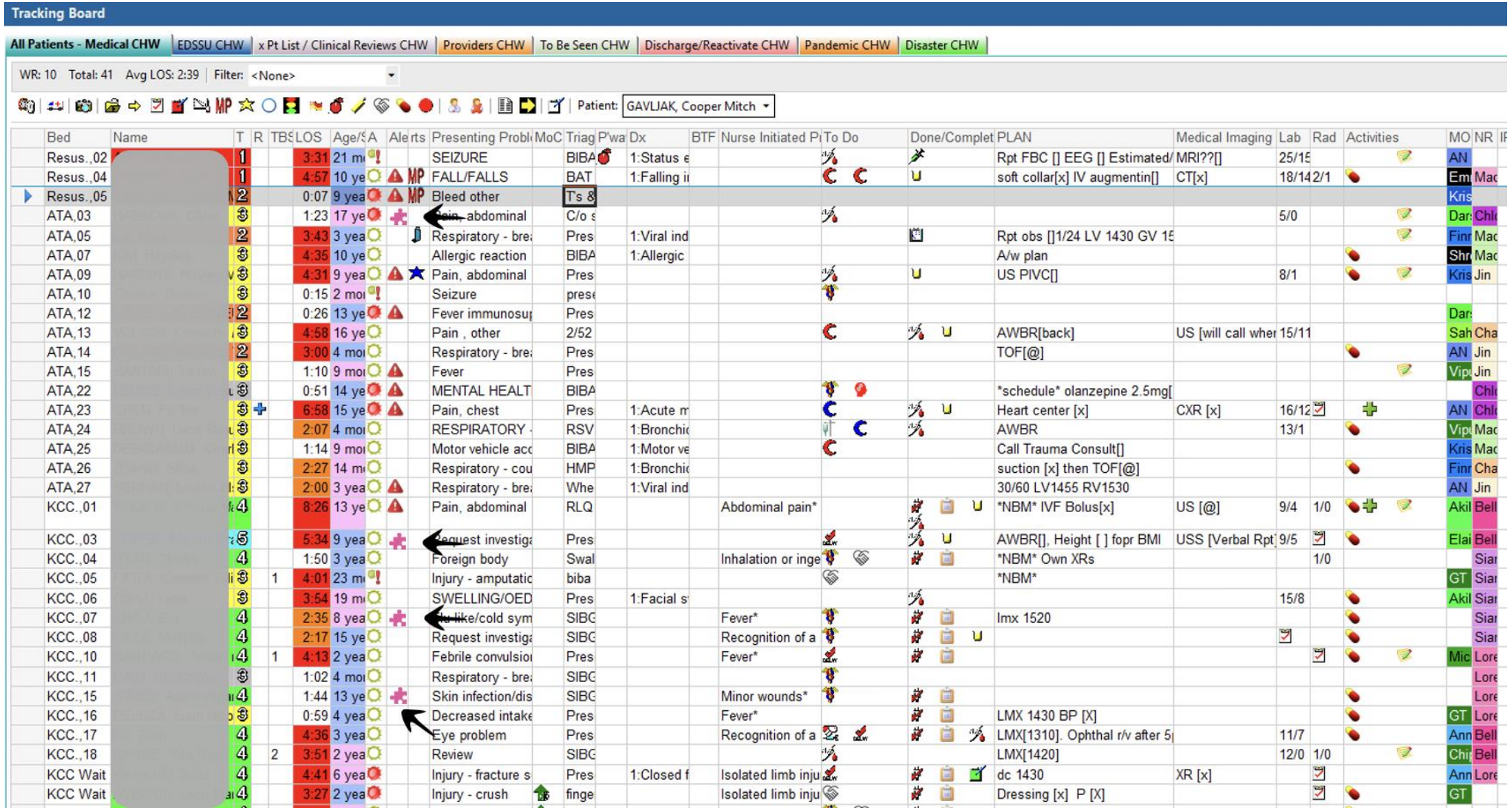
3. How do you know when I am escalating and getting upset?

4. What calms me down?

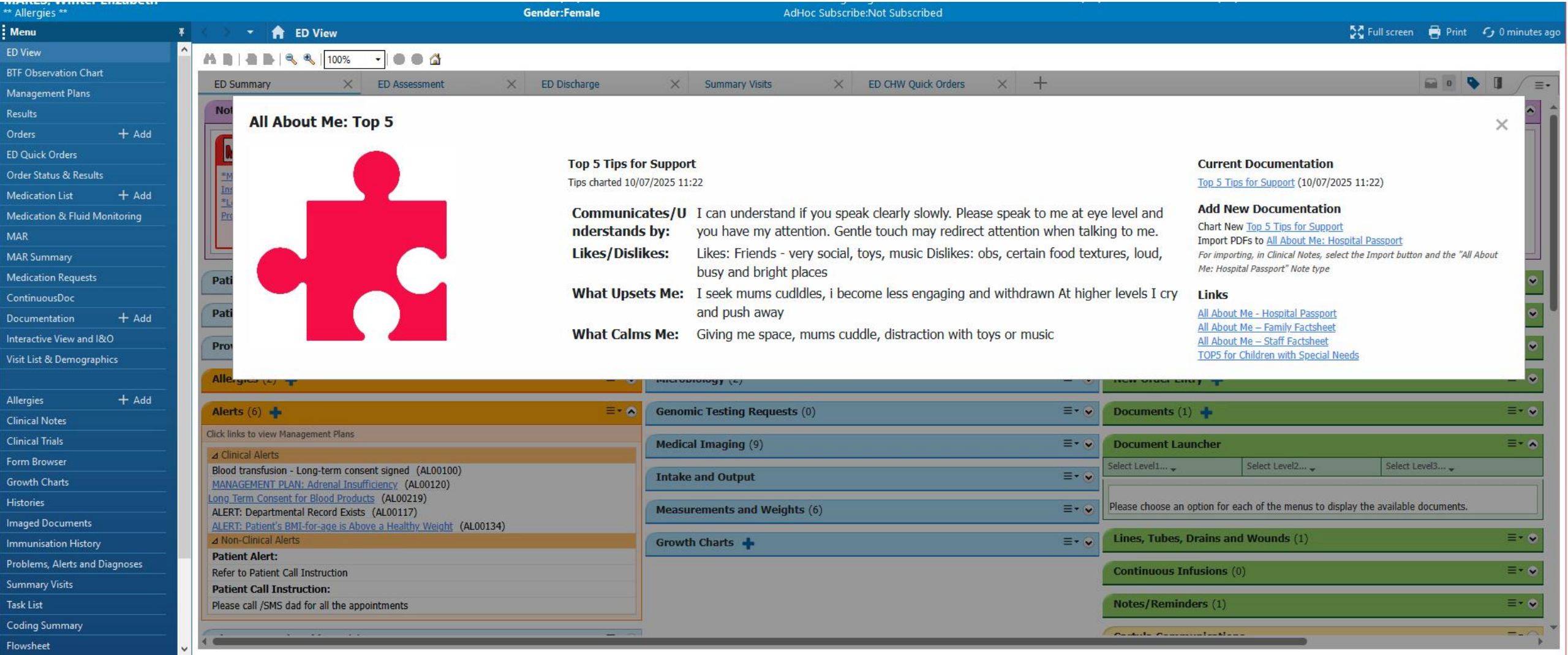
5. Any other useful information: eg about me, how I go with procedures, need for sedation, environmental changes etc.


** No Known Allergies **
Gender:Male
Menu
ED View
Full screen
Print
1 minutes ago
ED Summary
ED Assessment
ED Discharge
Summary Visits
Notifications
COVID-19
No COVID positive results or alerts are currently documented in last 28 days.
Click to Add or Review COVID-related results & documentation
Asthma Plans
*Asthma Action Plan (12/08/2025)
*Asthma Reducing Medication Plan (12/08/2025)
Priority Populations
Health Care Card Holder
Click here for information
All About Me
*All About Me - Top 5
(06/03/2024 11:03).
Show Details
Last Visit
CHW, Resp Fnctn Unit, (Outpatient)
Adm: 17/10/2025 13:51
D/C: 17/10/2025 23:59
Patient Demographics (Area Unique ID: 1323117)
Patient Contacts
Providers
Allergies (1)
Alerts (1)
Click links to view Management Plans
Clinical Alerts
ALERT: Patient's BMI-for-age is Above a Healthy Weight (AL00134)
Non-Clinical Alerts
There are no Patient or Social or Admin alerts entered for this patient.
Diagnoses and Problems (0)
Diagnoses (This Visit / Selected Visit)
Diagnosis
Date
Confirmation
Classification
No Diagnoses entered for this visit.
Chronic Problems (Across Visits)
Problem
Date
Confirmation
Classification
Observations
Pathology Results
Pathology Reports (0)
Microbiology (0)
Genomic Testing Requests (0)
Medical Imaging (4)
Intake and Output
Measurements and Weights (0)
Growth Charts
ED Pathways, Guidelines and Protocols
Outstanding Orders (0)
Outstanding Pathology Orders (0)
New Order Entry
Documents (3)
Document Launcher
Select Level1...
Select Level2...
Select Level3...
Please choose an option for each of the menus to display the available documents.
Lines, Tubes, Drains and Wounds (0)
Continuous Infusions (0)
Notes/Reminders (1)
ED View
BTF Observation Chart
Management Plans
Results
Orders
ED Quick Orders
Order Status & Results
Medication List
Medication & Fluid Monitoring
MAR
MAR Summary
Medication Requests
ContinuousDoc
Documentation
Interactive View and I&O
Visit List & Demographics
Allergies
Clinical Notes
Clinical Trials
Form Browser
Growth Charts
Histories
Imaged Documents
Immunisation History
Problems, Alerts and Diagnoses
Summary Visits
Task List
Coding Summary
Flowsheet

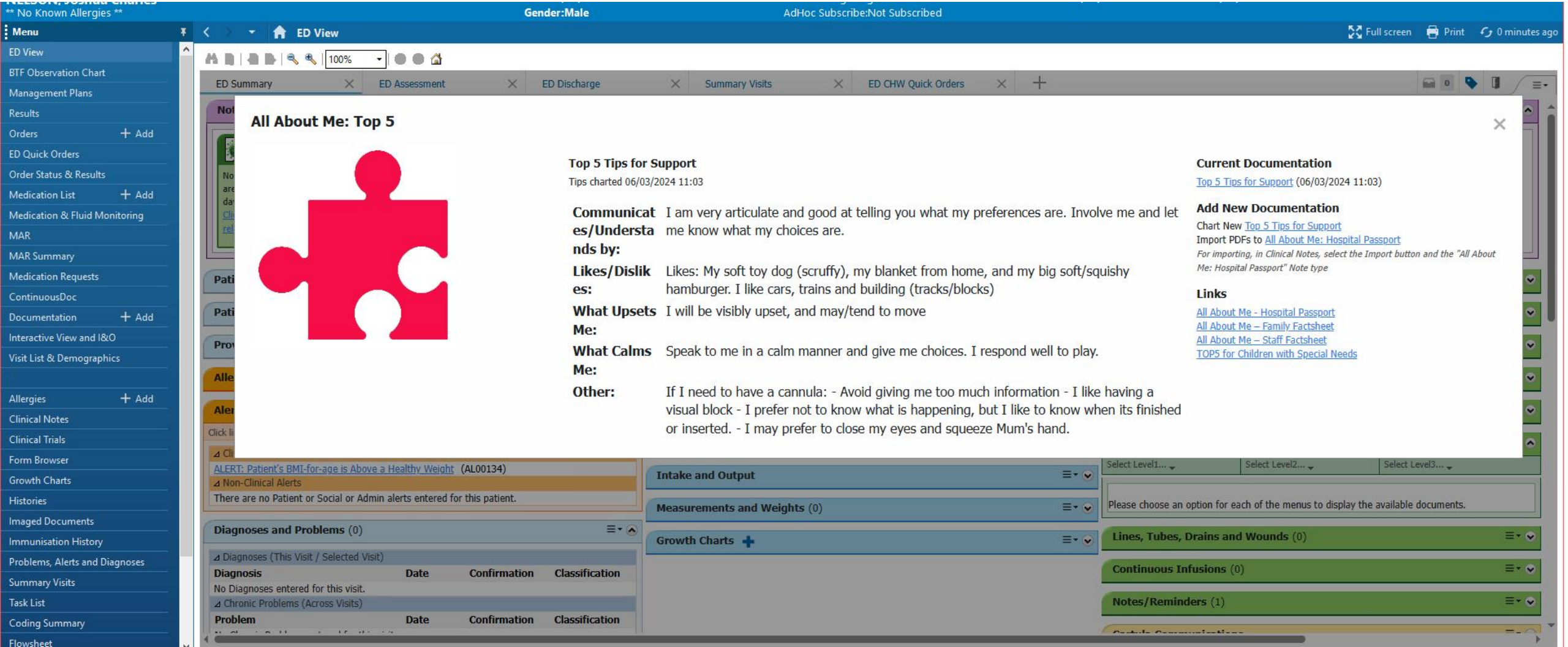
# Flagging system – Puzzle piece – Easy to identify



# Example 1

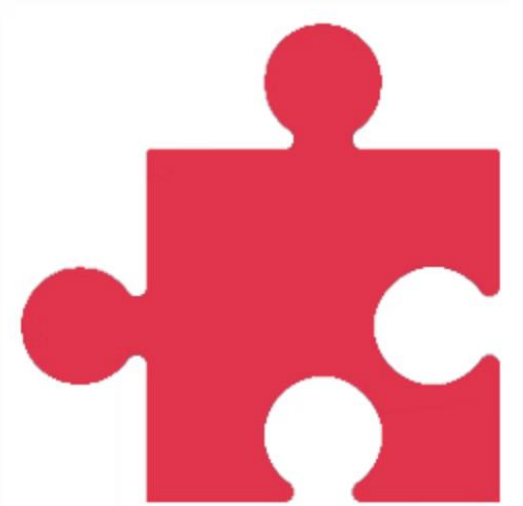

** Allergies **
Gender:Female
AdHoc Subscribe:Not Subscribed
Menu
ED View
Full screen
Print
0 minutes ago
ED Summary
ED Assessment
ED Discharge
Summary Visits
ED CHW Quick Orders
All About Me: Top 5
Top 5 Tips for Support
Tips charted 10/07/2025 11:22
Communicates/Understands by: I can understand if you speak clearly slowly. Please speak to me at eye level and you have my attention. Gentle touch may redirect attention when talking to me.
Likes/Dislikes: Likes: Friends - very social, toys, music Dislikes: obs, certain food textures, loud, busy and bright places
What Upsets Me: I seek mums cudldles, i become less engaging and withdrawn At higher levels I cry and push away
What Calms Me: Giving me space, mums cuddle, distraction with toys or music
Current Documentation
Top 5 Tips for Support (10/07/2025 11:22)
Add New Documentation
Chart New Top 5 Tips for Support
Import PDFs to All About Me: Hospital Passport
For importing, in Clinical Notes, select the Import button and the "All About Me: Hospital Passport" Note type
Links
All About Me - Hospital Passport
All About Me – Family Factsheet
All About Me – Staff Factsheet
TOP5 for Children with Special Needs
ED View
BTF Observation Chart
Management Plans
Results
Orders
ED Quick Orders
Order Status & Results
Medication List
Medication & Fluid Monitoring
MAR
MAR Summary
Medication Requests
ContinuousDoc
Documentation
Interactive View and I&O
Visit List & Demographics
Allergies
Clinical Notes
Clinical Trials
Form Browser
Growth Charts
Histories
Imaged Documents
Immunisation History
Problems, Alerts and Diagnoses
Summary Visits
Task List
Coding Summary
Flowsheet
Alerts (6)
Click links to view Management Plans
Clinical Alerts
Blood transfusion - Long-term consent signed (AL00100)
MANAGEMENT PLAN: Adrenal Insufficiency (AL00120)
Long Term Consent for Blood Products (AL00219)
ALERT: Departmental Record Exists (AL00117)
ALERT: Patient's BMI-for-age is Above a Healthy Weight (AL00134)
Non-Clinical Alerts
Patient Alert:
Refer to Patient Call Instruction
Patient Call Instruction:
Please call /SMS dad for all the appointments
Genomic Testing Requests (0)
Medical Imaging (9)
Intake and Output
Measurements and Weights (6)
Growth Charts
Documents (1)
Document Launcher
Select Level1...
Select Level2...
Select Level3...
Please choose an option for each of the menus to display the available documents.
Lines, Tubes, Drains and Wounds (1)
Continuous Infusions (0)
Notes/Reminders (1)

# Example 2


** No Known Allergies **
Gender:Male
AdHoc Subscribe:Not Subscribed
Menu
ED View
Full screen
Print
0 minutes ago
ED Summary
ED Assessment
ED Discharge
Summary Visits
ED CHW Quick Orders
All About Me: Top 5
Top 5 Tips for Support
Tips charted 06/03/2024 11:03
Communicates/Understands by: I am very articulate and good at telling you what my preferences are. Involve me and let me know what my choices are.
Likes/Dislikes: Likes: My soft toy dog (scruffy), my blanket from home, and my big soft/squishy hamburger. I like cars, trains and building (tracks/blocks)
What Upsets Me: I will be visibly upset, and may/tend to move
What Calms Me: Speak to me in a calm manner and give me choices. I respond well to play.
Other: If I need to have a cannula: - Avoid giving me too much information - I like having a visual block - I prefer not to know what is happening, but I like to know when its finished or inserted. - I may prefer to close my eyes and squeeze Mum's hand.
Current Documentation
Top 5 Tips for Support (06/03/2024 11:03)
Add New Documentation
Chart New Top 5 Tips for Support
Import PDFs to All About Me: Hospital Passport
For importing, in Clinical Notes, select the Import button and the "All About Me: Hospital Passport" Note type
Links
All About Me - Hospital Passport
All About Me – Family Factsheet
All About Me – Staff Factsheet
TOP5 for Children with Special Needs
Intake and Output
Measurements and Weights (0)
Growth Charts
Diagnoses and Problems (0)
Lines, Tubes, Drains and Wounds (0)
Continuous Infusions (0)
Notes/Reminders (1)

# Example 3

**All About Me: Top 5**



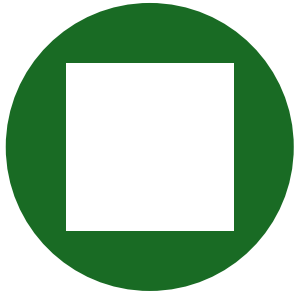
**Top 5 Tips for Support**

Tips charted 08/10/2024 09:17

| | |
|---|---|
| **Communicates/Understands by:** | I have good receptive language, please speak to me in simple sentences in calm and compassionate voice. My expressive language is improving and i can use single words for common needs (hungy, drink, toilet) and use gestures to point and indicate needs |
| **Likes/Dislikes:** | I love the wiggles, and musical instruments I dislike stern voices, loud noises, busy rooms I dont like needles, or hearing the word needles (please avoid) |
| **What Upsets Me:** | I become less responsive, repeat words or sounds (echolalia), pace, increase volume in tone When I am very upset I throw things and scream |
| **What Calms Me:** | Being calm and compassionate, I love affectionate hugs When I am in rage: please give me a quiet room, mum will give me a big hug |
| **Other:** | explain before doing things, have mum or dad in room, They will hug me and coach me throught the procedure Catapress might help as a pre medications |

# Evaluations

Motivated change program interviews and observational studies in pre and post intervention periods



Themes relating to the Top 5 tile were extracted to determine utility and experience of use from parents and staff

Medical Student UNDA – Executive Dean Scholarship
Data analysis of backend data from EMR

ED Data 18 months post intervention to look at sustainability of use and value

# Why the tile was needed

No questions were asked around the child's current development to flag any issues. No preparation of child. Obs 4

Mum stated that no one is listening to her concerns or willing to help her Obs 10.

..... you sometimes are worried that if they're gonna scream or,.... react and then..., **how they're going to kind of interpret that kind of behaviour** if they've seen behaviour of, like, these kids biting themselves or...Staff 4

..... it's just like you got feeling sometimes and you can't put a finger on it. Staff 4

# Parent & Staff Observations

*And **then she got the top 5 done**, …. I think that is a brilliant thing to have in place. **It was a more positive experience**, and I have ever experienced before. Parent 1.*

*[Parent] did not know that the **top 5 questions** were available online [ED electronic health record] but agreed that they are **a good description of the child.** Quote from Observation 4*

*They also mentioned that they noted that [the] **Top 5 flags in Radiology** and that they noted that **radiology will ring to find out more** about the child to assist with preparation. Obs 6*

*Staff highlighted that … supporting **the learning that is required to fill out Top 5** and care for these children. …..They were open to providing suggestion to assisting with development of Top 5 video. Observation 6*

# Outcomes of Tile

Was stationed in ATA as the ID icon appeared in First Net and TOP 5 completed for a patient. Obs 1

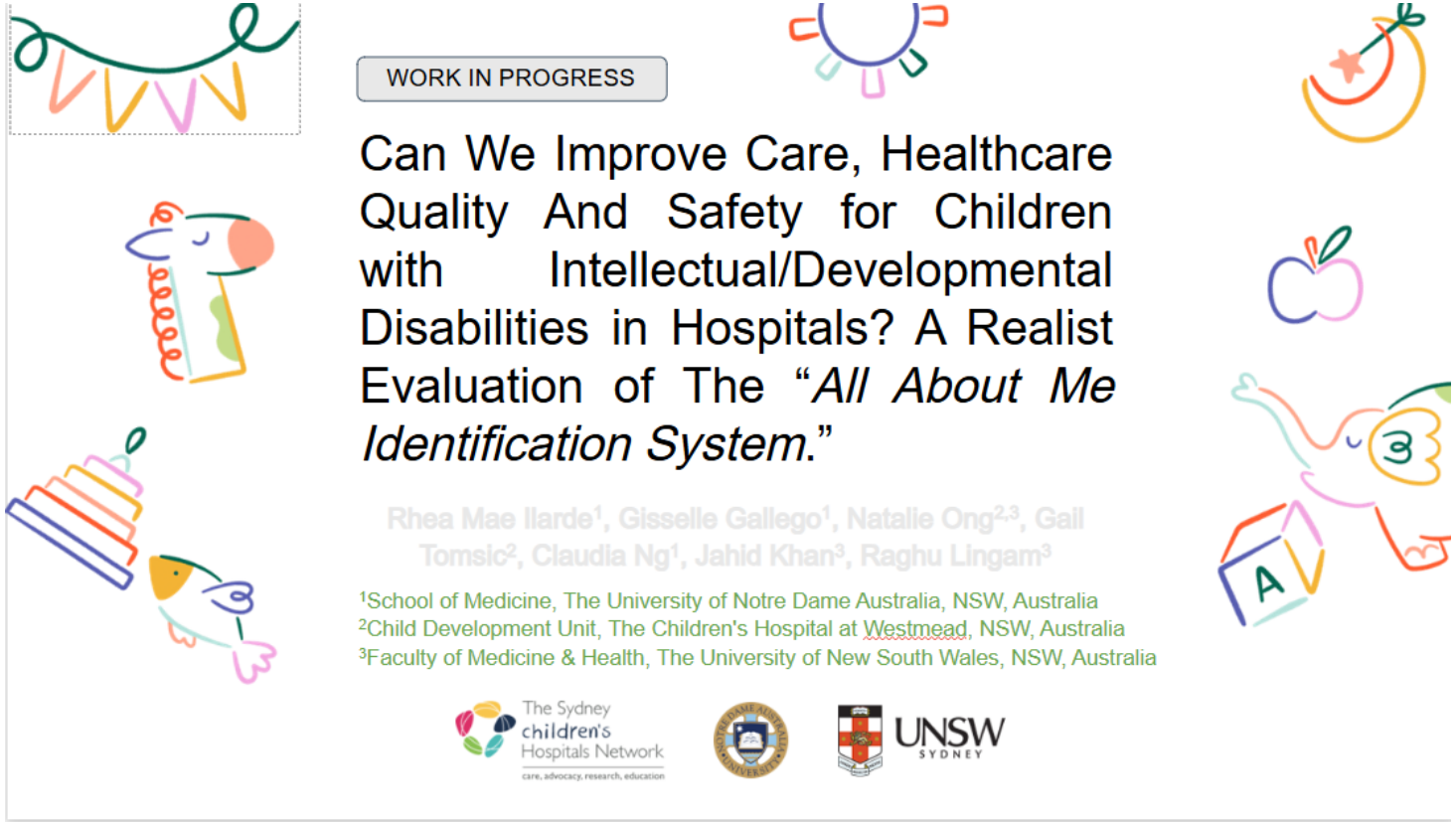
Noted to have observed on FirstNet two children with tile activated.  Obs 3

We've had a few changes in the department where there's an [electronic] tile now which pops up and once we put, you know, if we flag the child as having intellectual disability and it there's a page that pops up which gives you the top five things that the child likes. Staff 1

Every time I am in [KCC] and I see that there is a child with autism. When the triage nurse goes down to see them and seemed to realise we have this puzzle piece {I ask] Did you realise this is how it works? Like you do not have to put a lot of information on because people can always add to it as time goes by. Staff 5

# Analysis of EMR data: Student Project

- Like to acknowledge the support of the following:
- Rhea Ilarde, UNDA scholarship
- Giselle Gallego
- Jahid Kan
- Raghu Lingham



# Methodology

THE SYDNEY CHILDREN'S HOSPITAL NETWORK (SCHN), A TERTIARY & QUATERNARY HEALTH SERVICE WITHIN NSW THAT PROVIDES CARE TO VULNERABLE PAEDIATRIC POPULATIONS.

CYP WITH ID/IDD (0-18 YEARS), ADMITTED TO SCHN, AND HAD AN ALL ABOUT ME TILE BETWEEN NOVEMBER 2023-NOVEMBER 2024

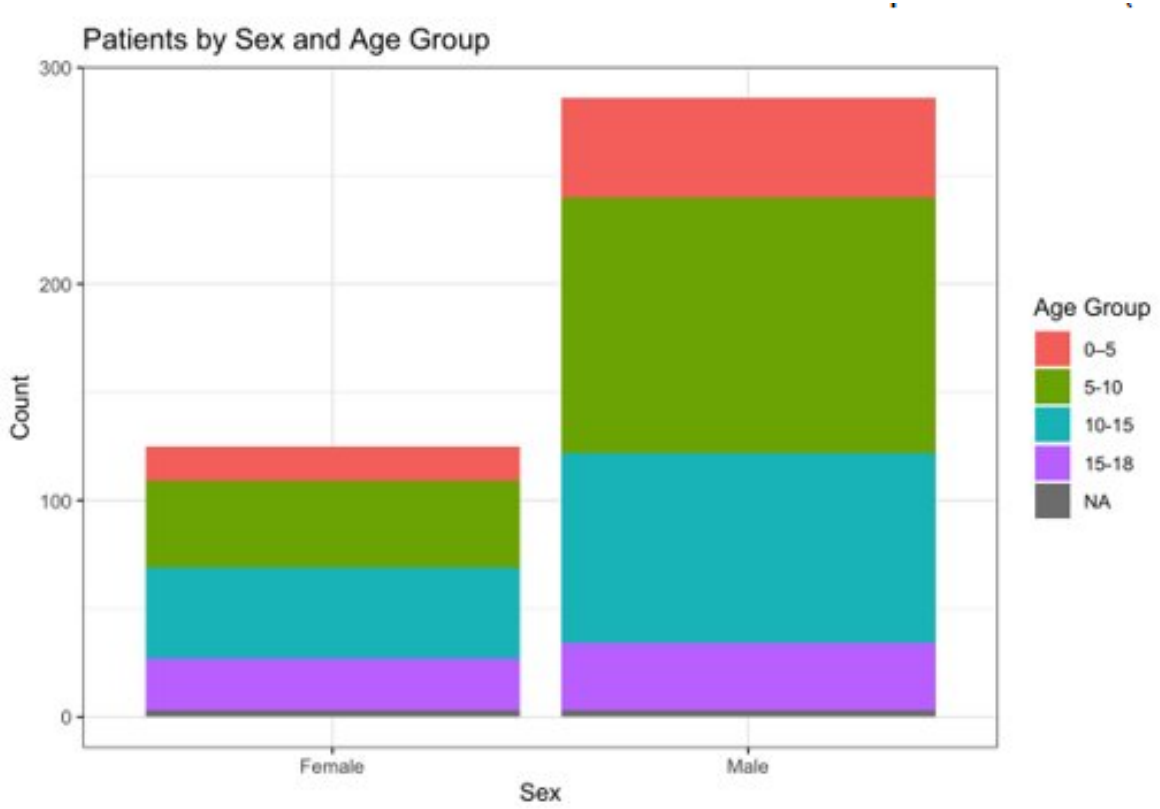
# Results

2,366 Actual presentations (N=2366)

411 Unique patients identified (n=411)

# Results: Demographic factors

- 70% of the patients were boys
- average age was 9.64±4.17 (SD)
- Age range is 1.5 to 18.5 years
- 371  spoke English at home
- 21 other languages
- 11 required an interpreter



# **Results: Demographic factors**
Counts at a patient-level (n=411)

25% Were under National Disability Insurance Scheme (NDIS)

8% Identified with an indigenous background

11 patients were considered out-of-home care (OOHC)

# Results:

Counts at a presentation-level (n=2,366)

| | Emergency (n=340) | Inpatient (n=631) | Outpatient (n=1395) | Total (N=2366) |
|---|---|---|---|---|
| **Documentation** | | | | |
| All About Me Tile | 328 | 554 | 1261 | 2143 (90%) |
| Hospital Passport | 9 | 73 | 118 | 200 (8%) |
| After hours Medical Progress Note | 3 | 4 | 16 | 23 (0.97%) |
| **Tile Completion (All TOP5 tiles filled)** | | | | |
| Yes | 221 | 407 | 1026 | 1654 (69%) |
| No | 119 | 224 | 369 | 712 (31%) |

# Who is completing tile
# Counts at a presentation-level (n=2,366)

JUNIOR DOCTORS IN ED

ALLIED HEALTH INPATIENT

NURSES OUTPATIENT

# Results:

Counts at a presentation-level (n=2,366)

In the emergency department

- Gastrointestinal
- Respiratory / Cardiac
- Neurology
- ENT
- Behavioural

In Inpatient wards, the most common

- Gastrointestinal
- Respiratory / Cardiac
- Neurology
- Dental
- Musculoskeletal

**In Emergency, the clinical groups with the most comorbidity / co-presenting symptoms are…**

1. Behavioural
2. GIT
3. Inflammatory
4. Respiratory/Cardiac
5. Haematology

**In Inpatient, the clinical groups with the most comorbidity / co-presenting symptoms are…**

1. Neurology
2. GIT
3. Respiratory/Cardiac
4. Haematology
5. MSK

18 month post

# All About Me tile – Digital Alerts & Documentation – Staff Feedback 2025

"…the flagging with the puzzle piece has been useful to identify these children quickly early, knowing they may need extra TLC.."

"…being able to document the top five and a structured way, means I can hand it over to the next nurse which means the unique care can be continued.."

"Parents always have been pleasantly surprised when asked them these questions about their child… They feel heard…

# Informing SDPR Build

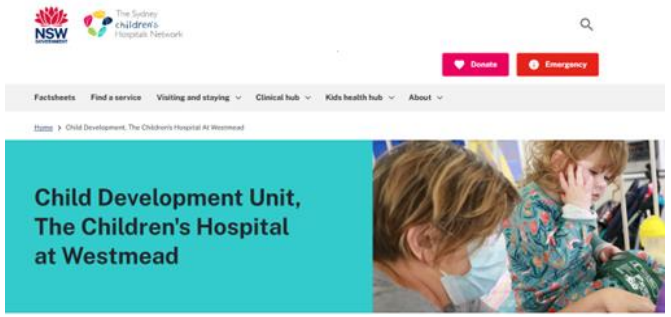
**Aug. 2025**

Focus Groups with key uses of the All About Me Tile Aug 2025 with represenatives

Embedded in Single Digital Patient Record build for release in Tranche A March 2026

**Mar. 2026**

# TOP 5 and Hospital Passport




# Conclusion

# References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# Thank You

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