



Patients as Partners-in-Care

**Strategies on how to engage
patients and families to improve
healthcare quality**

Hello from SPAN



SPAN Patient Advocates : What do we do?



- We are patients and caregivers who want to make a positive impact on healthcare by bringing forward the patient and family perspective to healthcare teams.

**We do what we do
because of a life-
changing illness**





Poll : Have you engaged patients and families in your healthcare improvement project?



Staff's view Patient's view



**Why you need
patient
engagement!**

If you need **User Experience** in your
Improvement Project...

...You will need **Patient Engagement**

Example of chemotherapy PIL project

Background

SPAN members collaborated with the Pharmacy team from National Cancer Centre to review and give suggestions on the wordings/layout of patient education materials for patients undergoing chemotherapy

Changes made: wordings were simplified, retaining the pertinent information and layout was revised to make it easier to read

Objective:

To produce patient education materials that are easily understood by patients

Members involved: Ms Ai Ling Sim-Devadas, Mr Chew Kim Soon, Ms Irene Gwee, Ms Khoo Sork Hoon, Mr Teo Kee Huat



Before

Possible Side Effects	Prevention & Management Strategies	Possible Side Effects	Prevention & Management Strategies
(A) IMMEDIATE (HOURS)		(B) EARLY (DAYS TO MONTHS)	
Pain or swelling at injection site (Extravasation)	Inform nursing staff immediately if you experience any pain, stinging, swelling or redness near or at the injection site. This means that drug is not going into the vein and may be leaking onto the skin. Urgent treatment is needed to treat blistering and ulceration of the area if this occurs.	Poor appetite	This may be worsened by a change in taste of food and/or nausea. Try different flavours of food and small frequent meals. For poor appetite, try to include nutritional supplements (eg Ensure®, Prosure®) into your diet.
		Constipation (bowel movement lesser than usual)	Drink more fluids and take enough fibre. If you are unable to pass motion / stools, you may take oral laxatives (eg lactulose, senna or bisacodyl) as needed.
Nausea and vomiting may occur during chemotherapy	Anti-vomiting medications will be given before chemotherapy.	Mouth sores / ulcers	Use a soft-bristled toothbrush. Use salt water to rinse your mouth at least three times a day after meals. Inform your doctor / pharmacist if mouth sores cause pain when you eat.
	Standby anti-vomiting / nausea medications will be given for you to bring home.	Tiredness / Fatigue – common in the first 1 to 2 wks after chemotherapy	Eat well and get enough sleep. Prioritize tasks to ensure you make the best use of your energy. Light exercises may help to reduce fatigue.
	To help relieve nausea, take small frequent meals. Avoid foods / smells that may make you feel nauseous, such as oily, fried food or strong-smelling food.	Low white blood counts i.e at a higher risk of having an infection.	Avoid crowded / poorly ventilated places and sick people. Practise good personal hygiene. See a doctor immediately if you develop a fever (38°C and above) or feel unwell.
Orange or Reddish coloured urine	Your urine will turn orange or red in colour. This is due to doxorubicin (one of the drugs given). It will return to its normal colour in 2 to 3 days.	Low platelet counts ie you may bruise or bleed more easily.	Try not to injure / cut yourself accidentally. Use a soft-bristled toothbrush as your gums may bleed more easily. Consult your pharmacist before taking any pain medications as some may increase your chances of bleeding.

- Heavy text, with jargons like ‘extravasation’
- Side-by-side layout for the (A)Immediate and (B) Early effects, making it more difficult to read

After

Possible Side Effects	Prevention & Management Strategies
DURING OR HOURS AFTER TREATMENT	
<i>Pain or swelling at injection site</i>	Inform your nurse immediately if you experience any pain, stinging, swelling or redness near or at the injection site.
<i>Nausea and vomiting may occur during chemotherapy</i>	Anti-vomiting medications will be given before chemotherapy and also will be given for you to bring home. To help relieve nausea, take small frequent meals. Avoid foods / smells that may make you feel nauseous, such as oily, fried food or strong-smelling food.
<i>Orange or Reddish coloured urine</i>	Your urine will turn orange or red in colour for 2 to 3 days. This is due to doxorubicin.
DAYS TO MONTHS AFTER TREATMENT	
<i>Poor appetite</i>	This may be worsened by a change in taste of food and/or nausea. Try different flavours of food and small frequent meals. For poor appetite, try to include nutritional supplements (eg Ensure®, Prosure®) into your diet.
<i>Constipation (bowel movement lesser than usual)</i>	Drink more fluids and take enough fibre. If you are unable to pass motion / stools, you may take oral laxatives (eg lactulose, senna or bisacodyl) as needed.
<i>Mouth sores / ulcers</i>	Use a soft-bristled toothbrush. Use salt water to rinse your mouth at least three times a day after meals. Inform your doctor / pharmacist if mouth sores cause pain when you eat.
<i>Tiredness / Fatigue</i>	Eat well and get enough sleep. Prioritize tasks to ensure you make the best use of your energy. Light exercises may help to reduce fatigue.
<i>Low white blood cell counts</i>	You may be more prone to infections. Avoid crowded / poorly ventilated places and people with infections. Practise good personal hygiene. Eat only well-cooked food. See a doctor immediately if you develop a fever (38° C and above) or feel unwell.
<i>Low platelet counts</i>	You may bruise or bleed easily. Be careful not to injure / cut yourself. Use a soft-bristled toothbrush as your gums may bleed more easily. Consult your pharmacist before taking any pain medications as some may increase your chances of bleeding.

- Wordings were simplified, retaining pertinent information
- Clearer explanation e.g. 'Immediate (hours)' was changed to 'During or hours after treatment'
- Layout was revised to make it more patient friendly

Past Projects by SPAN

National level

- ✓ Consultation by MOH Workgroup on Informed Consent
- ✓ Consultation by MOH Health Regulation Group on Consumer Edu Strategy
- ✓ Singapore Health Quality Service Awards 2020-2021 *(as judge/s)*
- ✓ Singapore Healthcare Management Congress 2019 *(as judge/s)*

Institutional level

- ✓ Future Outpatient Journey Taskforce
- ✓ Elective Surgery Taskforce
- ✓ SGH Business Office service transformation discussions
- ✓ NHCS Focus Group Discussion
- ✓ Consultation on Patient Education Materials





A

Abscess

Layman's explanation
Bump on skin or a painful swelling

Used in a sentence
If you see a bump on your skin or a painful swelling, please tell your doctor or nurse.



Ambulant

Layman's explanation
Able to move around by himself

Used in a sentence
Mr Tan is able to move around by himself.

Acute

Layman's explanation
Sudden

Used in a sentence
If you feel a sudden loss of hearing in the next few weeks after your discharge, please go to the nearest A&E immediately.

Ambulate

Layman's explanation
Moving around

Used in a sentence
Your father needs help with moving around.

Acute Retention of Urine (ARU)

Layman's explanation
Cannot pass urine properly

Used in a sentence
If you cannot pass urine properly, please see the doctor.

Asymptomatic Microscopic Haematuria (AMH)

Layman's explanation
Found blood in your urine during the test without you having any urine symptoms.

Advance Care Planning (ACP)

Layman's explanation
How you would like to be cared for should you become unable to speak for yourself

Used in a sentence
We would like to discuss and write down how you would like to be cared for should you become unable to speak for yourself.

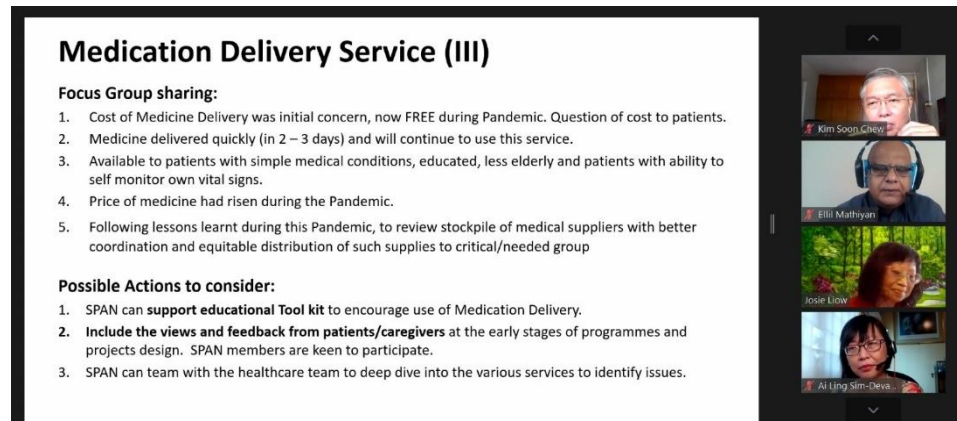
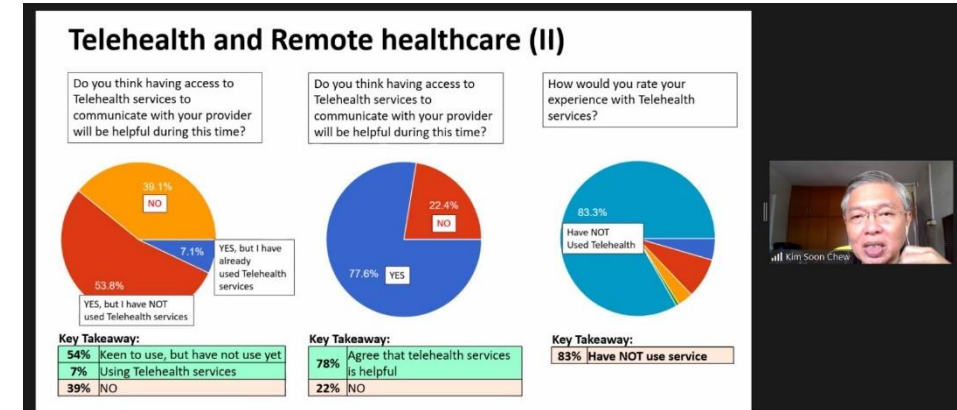
Used in a sentence
We found blood in your urine during the test without you having any urine symptoms.

Plain English Glossary

Building a glossary of 150 commonly used medical terms and jargon and its layman's explanation to improve communication

Presentation of Covid-19 Patient Survey findings

- In Aug 2020, Josie and Kim Soon conducted a **survey** among **156 patients and caregivers** to find out their patient experience during Covid-19
- A small **focus group discussion** (FGD) was later convened to deep dive into certain topics
- Apart from presenting the findings from the survey and FGD to the **SingHealth management in Oct 2020**, they later presented the findings at various **cluster-level meetings for colleagues from the various Office of Patient Experience and Group Communications teams in Jan 2021** to give insight into the sentiments on the ground and to identify proposed actions.



Snapshot of SPAN today!

- 40 Patient Advocates (patients & families) from all walks of life
- Most of us have gone through a life-changing illness
- We participate in workgroups, committees, talks and healthcare events.
- Skills-building for Patient Advocates – Patient Advocates Communication Training, Quality Improvement, Design Thinking, Story-telling, Patient-centered Research, etc.....

Value of having patients and families onboard

- Serve as a sounding board for your initiatives.
- Provide input from the user perspective.
- Shed light on any blind spots.

Make care safer and better!

How do you
engage
patients?



Spectrum of Engagement



“We keep you informed.”

- Brochures
- Fact Sheets
- Website
- Social Media
- Newsletter

“We listen & acknowledge your feedback.”

- Feedback forms
- Consultative feedback sessions
- Focus Groups
- Surveys

“We work with you to ensure your concerns and hopes are reflected .”

- Workshops

“We co-design and co-produce the solution with you.”

- Committees
- Workgroups
- Project Teams



What does it mean for you



Inform



“We keep you informed.”

- Brochures
- Fact Sheets
- Website
- Social Media
- Newsletter



Ask

“We listen & acknowledge your feedback.”

- Feedback forms
- Consultative feedback sessions
- Focus Groups
- Surveys



Co-opt

“We work with you to ensure your concerns and hopes are reflected .”

- Workshops



Team-up

“We co-design and co-produce the solution with you.”

- Committees
- Workgroups
- Project Teams



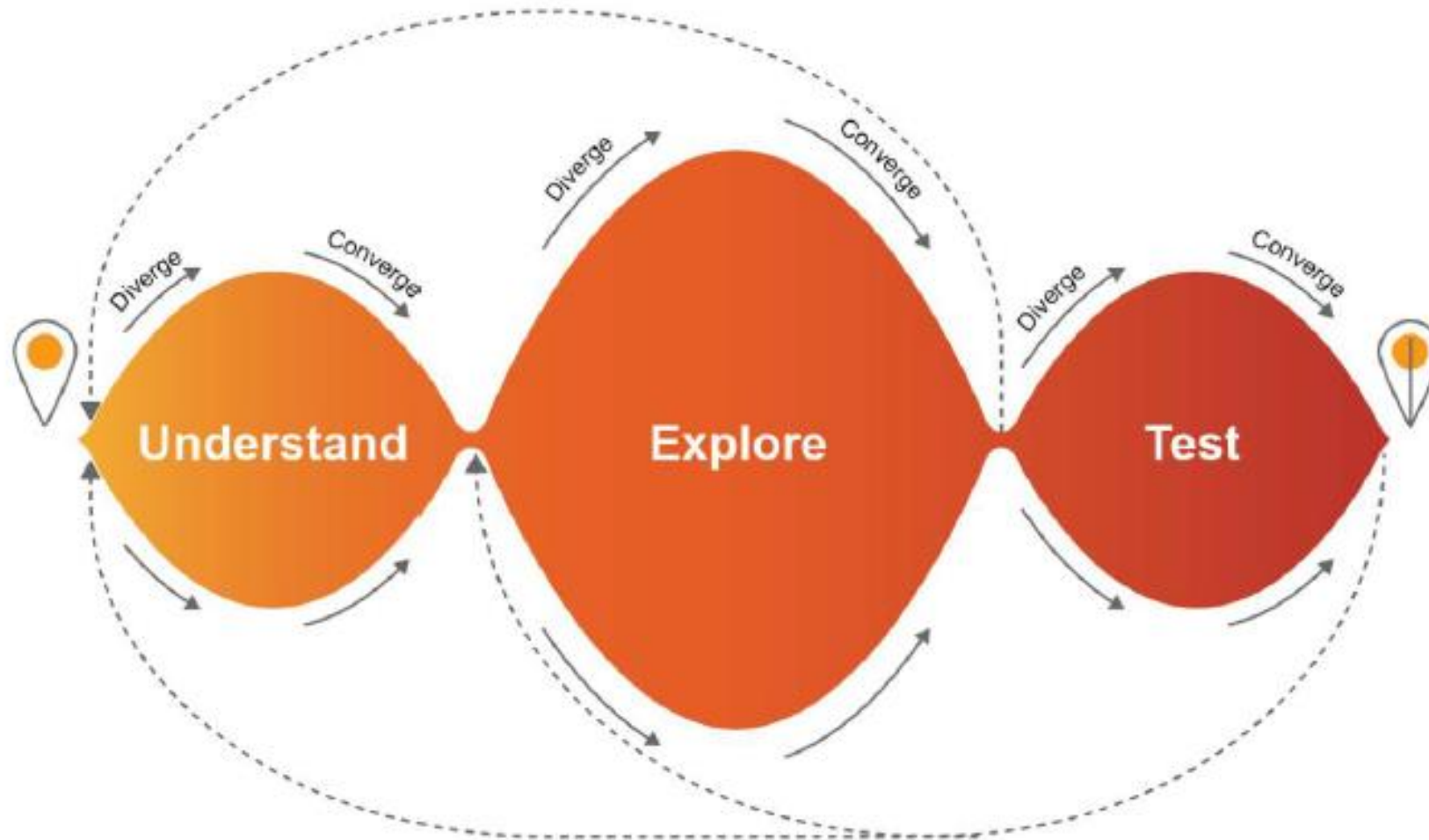


**Human Centred Design / Experience-Based
Design / Design Thinking**

Design Thinking Approach

Design Thinking approaches insight gathering and solutioning through **co-designing and co-producing**.

It facilitates the uncovering of latent needs that may not be immediately apparent to these users.



Empathy : Some methods to understand patient experience

- Interviews
- Focus groups
- User observations / Shadowing
- Journey mapping
- Journal

How to get patients and families involved in your project?

SPAN

Patients & Caregivers in your clinic/ward

Patient Support Groups

If you need advice on how to involve patients and families...



Contact

- SPAN Secretariat & IPSQ

partnersincare@singhealth.com.sg

At recruitment...

- Be clear about your project objective and the role you will like the patient/family to play in the project.
- Decide what is the patient profile and qualities you need.

And when you have them onboard...

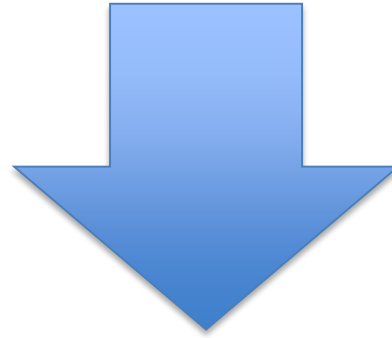
- Provide clear goals of the project to the patients/families.
- Provide them with supporting information to consider/review before the session. Send them an information pack (without healthcare jargon – or explain them).

And when you have them onboard...

- Create open and conducive environment that build trust and encourage them to share.
- Listen and engage with them
- Ask the right questions!

Going beyond...

“What is the Matter”



“What Matters to You”

Asking Open Questions to Understand What Matters

“Was sufficient information provided to you when you were informed of your diagnosis?”

“Tell me more about what was going through your mind when you were told the diagnosis. How did you feel?”

Asking Open Questions to Understand What Matters

“How long did you have to wait for your consultation at the A&E?” or “Was the nurse/doctor able to address your concerns?”

“What causes you anxiety at the A&E?”

7 Steps to Great Patient Engagement in your Project

Start

Start from project design – how can you include patients and families

Recruit

Recruit patients, families and patient advocates – Seek advice from SPAN Secretariat and IPSQ

Empathise

Empathise by understanding patients and families perspective and experience through insight gathering methods

Create

Create open and conducive environment for open discussions and to build trust

Ask

Ask the right questions – open questions on “What matters to the patient”

Engage

Listen and have honest conversation

Co-produce

Develop and test solutions collaboratively



SingHealth Patient Advocacy Network



SingHealth



And finally...

Keep us updated on the progress of the project.

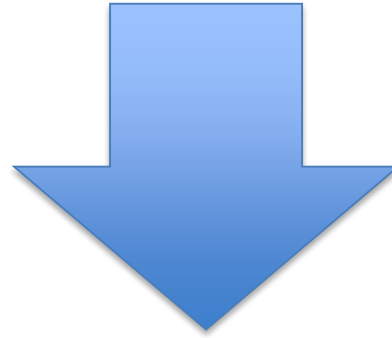




It will take more time and resources but it will be more rewarding!

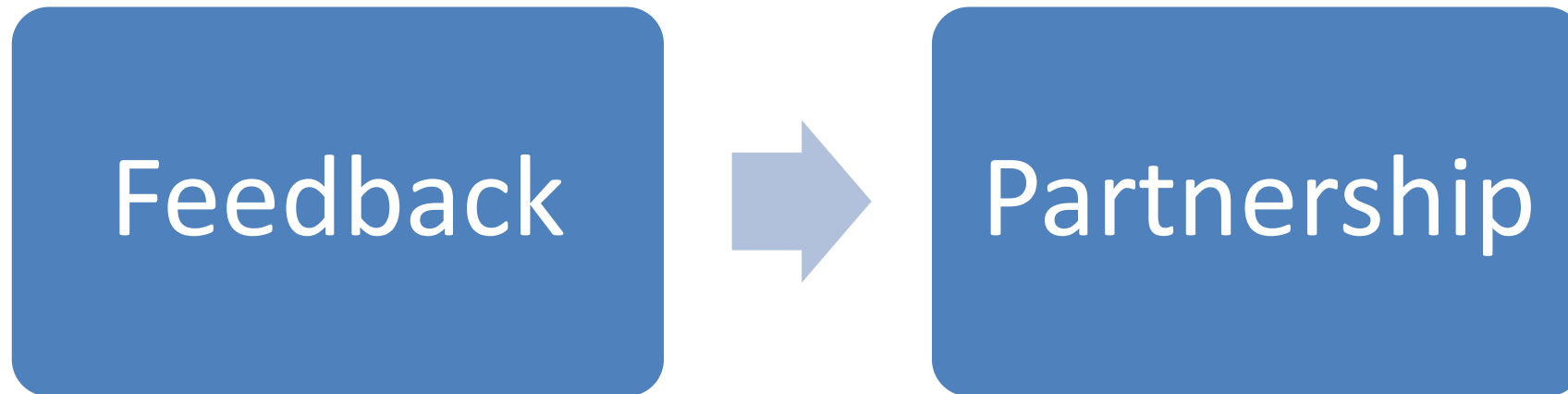
Going beyond...

“What is the Matter”

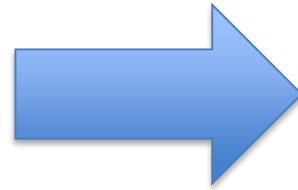


“What Matters to You”

Going beyond...



Going beyond...



Ticking the Patient Engagement Box

Practising Authentic Patient Engagement

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Patient Advocates help to



REFRAME PROBLEMS



GENERATE SOLUTIONS



IMAGINE NEW POSSIBILITIES

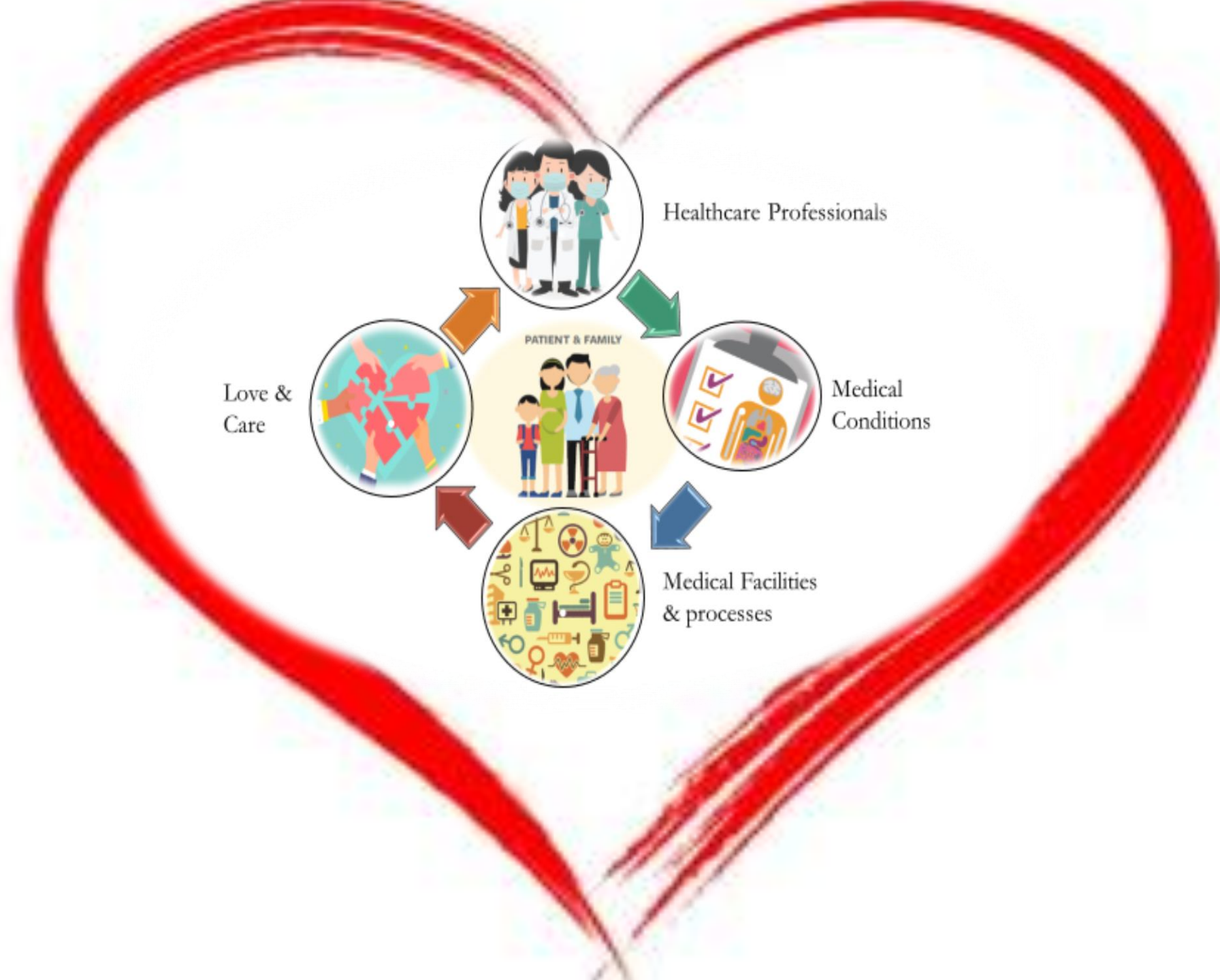


Involving Patients and Families in your projects is the 1st step to transforming healthcare



Josie's Insights







IGNITE



做而易懂。 Involve me and I will understand.

INVOLVE
Me



INFORM

