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with patients**



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# Care at end of life in intensive care What matters to patients matters to staff !

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SCOTTISH QUALITY AND SAFETY FELLOW COHORT 10

# Context



# Objectives

1. Use a reductive approach to a complex problem and identify modifiable and non modifiable factors
- 2 To engage all members of a team to collaborate to work towards a shared goal
- 3 .To use value based listening to improve care and peer support

# Critical incident with prescribing at end of life- March 2020

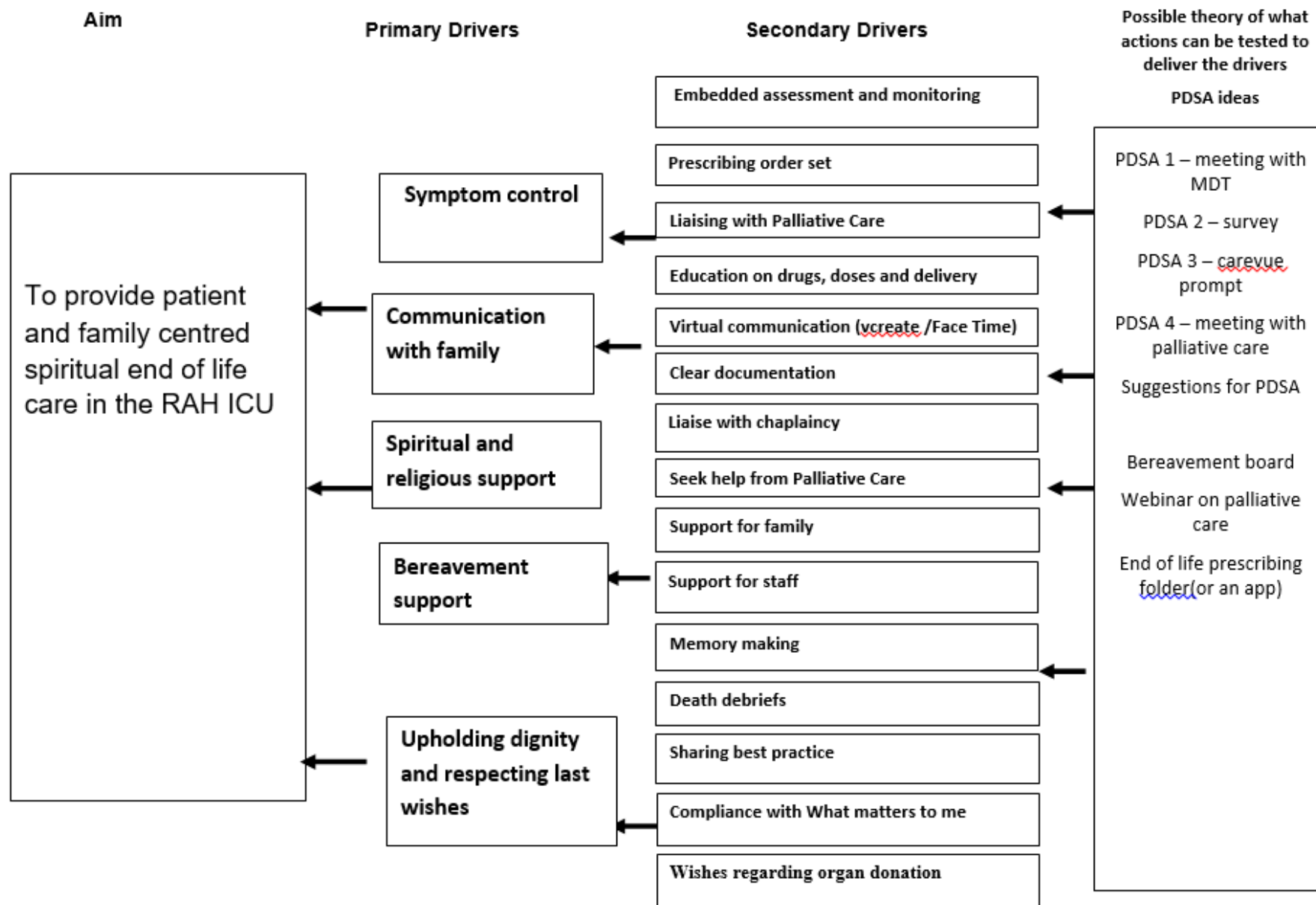






# AUTONOMY

## Driver Diagram for improving EOL care in RAH ICU





# End of life prescribing

- ▶ 15-20% of our patients will die on the unit
- ▶ 'A good death, as well as a good life, is important'
- ▶ Unclear at the RAH what the prescribing practices are
  - ▶ End of life tools being used?
  - ▶ What drugs are being used?
  - ▶ Inconsistencies across patients?
  - ▶ Prescribing should be symptom led – is it?

# What did we look at?

- ▶ Carevue End of life care plan initiated
- ▶ End of life prescribing bundle used?
- ▶ Routine and unnecessary medications stopped?
- ▶ Were patients maintained on their current sedation plan i.e. Alfentanil and propofol usually. Or were patients switched to Midazolam and Morphine?
- ▶ Briefly looked at levels of infusions used – would be easy to go back and assess further.

# General Carevue tools used and prescribing

End of life care plan initiated?

Yes: 39 (95%)

No: 2 (5%)

End of life prescribing bundle used?

Yes: 25 (61%)

No: 16 (39%)

Other medications stopped?

Yes: 25 (61%)

No: 16 (39%)

# Specific prescribing

## Propofol stopped?

Yes: 20 (49%)

No: 19 (46%)

Yes but still on script: 2 (5%)

## Alfentanil stopped?

Yes: 25 (61%)

No: 16 (39%)

## Midaz/Morphine started?

Yes: 19 (46%)

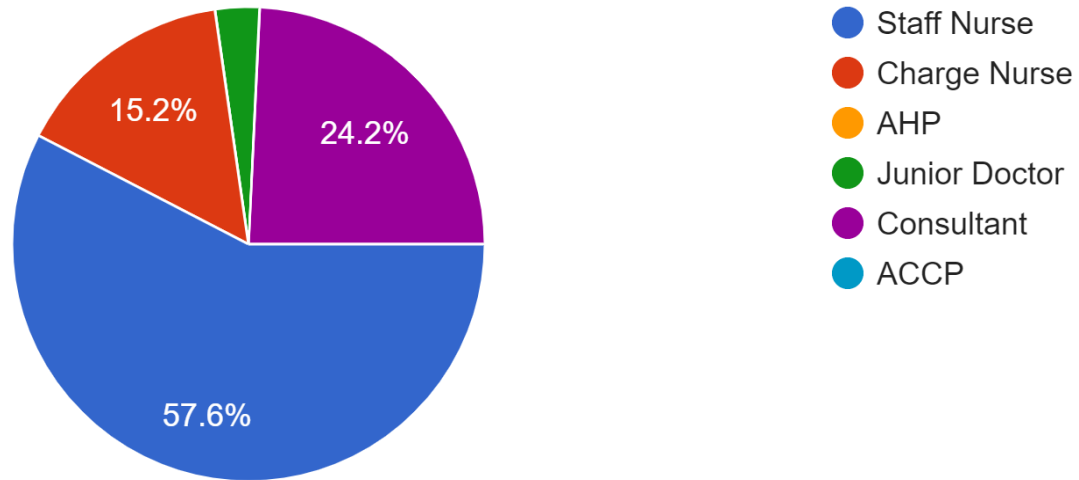
No: 17 (42%)

Prescribed not given: 5 (12%)

Morphine rate range 0.5mg/hr – 30mg/hr. Majority <5mg/hr

# Online questionnaire

- ↓ Sent to all MDT staff working in RAH ICU
- ↓ 33 respondents



# In your experience, do patients in our unit at the end of life experience a dignified death?

- ↴ Sometimes - 13
- ↴ All the time - 18
- ↴ Never - 0

Perhaps the most important question from the whole questionnaire. One of our primary aims should be achieving a dignified death for every one of our patients, and this shows we have a long way to go.



Are you aware there is an order set on Carevue for EOL prescribing?

↓ 9 respondents did not know there was an order set

In your experience, do find anticipatory medications prescribed for all end of life patients?

↓ Overwhelmingly staff felt anticipatory meds are only 'sometimes' prescribed.

Do you feel comfortable titrating medications to achieve comfort and analgesia for patients on EOL care?

↓ Yes 26

↓ No 7



# How do you think we should administer midazolam and morphine for patients on EOL care?

Wide variety of responses. General feeling is that it should not be prescriptive and it is patient and situation dependant, and all options should be available. Small trend towards syringe drivers.

	<b>Staff Nurse</b>	<b>Charge Nurse</b>	<b>Consultant</b>
<b>Syringe driver</b>	12	3	7
<b>Continuous IV infusion</b>	8	3	3
<b>Bolus doses</b>	2	1	3

# Are you confident using syringe drivers? Would you be interested in receiving training?

- ↴ 13 respondents confident in syringe driver use
- ↴ 19 respondents not confident in their use
- ↴ 28 respondents would be interested in receiving training
- ↴ When asked if any other drugs might be useful in EOL care 5 respondents mentioned an anti-emetic specifically  
Levomepromazine

# Spiritual Care

Are you satisfied with the spiritual support we offer our families?

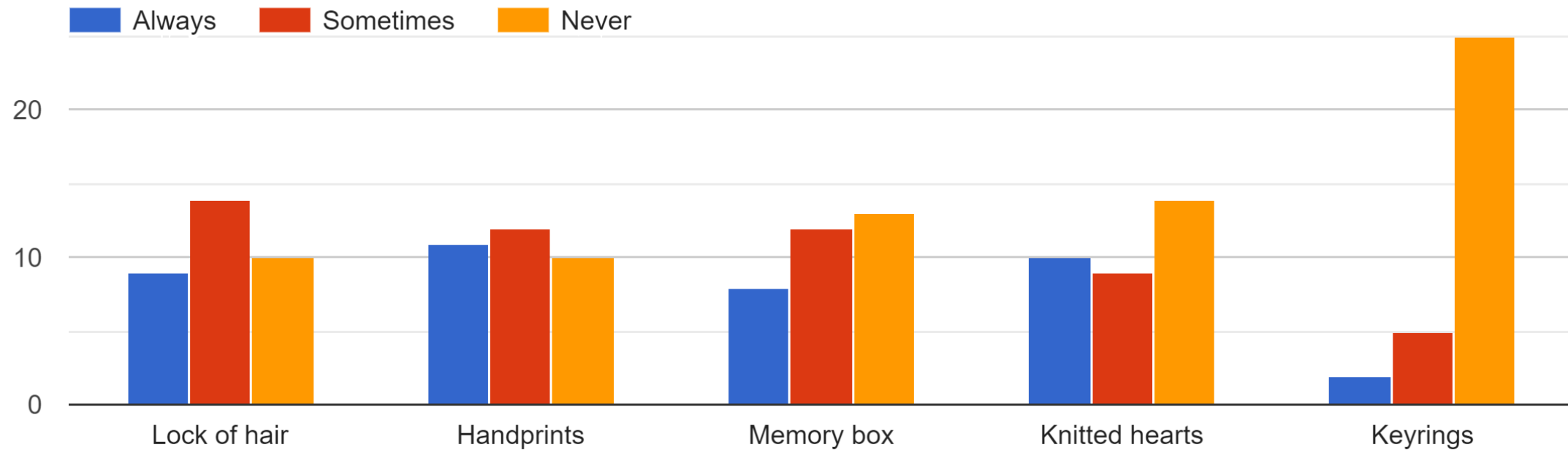
↵ Sometimes - 21

↵ All of the time - 10

↵ Never - 1

# Keepsakes

Do you ask families if they want



# Areas requested for more teaching/training

- ↵ Syringe drivers
- ↵ Conversion tables for drugs
- ↵ Clear guidelines and consensus surrounding prescribing
- ↵ Communication skills on delivering bad news/communicating with families surrounding death and dying
- ↵ Multiple comments about the desire to have teaching direct from palliative care specialists
- ↵ Spiritual care - availability and how to deliver it

# Staff bereavement support

- ↯ Obvious room for improvement in this area.
- ↯ Overall dissatisfaction with support offered and overwhelmingly respondents felt there isn't any support available or if there is, they did not know it existed or how to access it.

# What staff support do you find helpful at present?

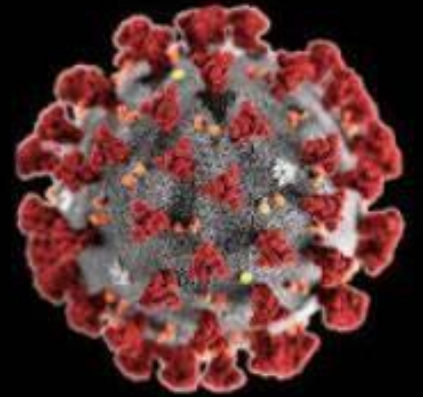
- ↴ Lots of respondents stated there was none at present, or described it as 'poor'
- ↴ Informal conversations with colleagues and informal peer support highlighted by respondents as main area of current support.
- ↴ Lack of debriefs highlighted as area for improvement
- ↴ "I feel the care for staff is somewhat over looked at times"



# Other suggestions from the questionnaire

- ↴ Greater consistency and standardising the approach to EOL
- ↴ Greater communication across the MDT, with shared decision making
- ↴ The use of debriefs highlighted multiple times
- ↴ Discussions about self care

# What emerged from this



# We said – we listened – we made a change

EOL  
prescribing

Prescribing  
prompt

Education

Staff support

Psychologist

Spiritual  
Lead

Bereavement  
support

Memorial  
service

Business  
case

Memory  
making

Keepsakes

Organ  
Donation

# Humanising end of life care



Ensure we know what matters to them

Create memories for families

Gift of life – approach every family about organ donation

# COMFRT tool

C onsensus decision that focus of care needs to be changed

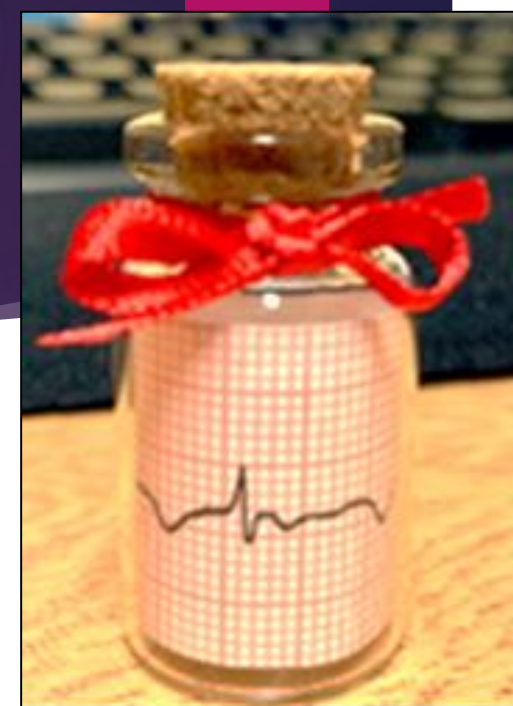
O rgan donation considered

M edical documentation

F amily-space and time

R eligious and Spiritual needs

T asks – memory making , certificates and personal belongings



The Order Of St John award presented to families at an annual ceremony held in all 12 regions within the UK

The gold Heart pins that are given to our donor families to honour their loved one

The finger print family trees that we offer to our donor families

The heart beat in a bottle we give our donor families if they wish



# Teddies and handprints





# We Remember: A Critical Care Covid 19 Remembrance Service

Dr Ross Norris, Dr Jacqueline McCarthy, Dr David Gray & Dr Radha Sundaram  
Royal Alexandra Hospital, NHS Greater Glasgow and Clyde

## Background

There is increasing recognition that palliative care when provided appropriately to critically ill patients with life limiting illness can not only offer physical, psychosocial and spiritual care to patients but also helps improve family and staff satisfaction. This recognition and direct feedback from staff led to the establishment of a multi-disciplinary palliative care quality improvement group within the critical care department at the Royal Alexandra Hospital in Paisley.

An initial staff survey was distributed within the unit to identify areas for improvement. The feedback showed spiritual and bereavement support as key areas for improvement.

Based on this feedback, the decision was made to host a remembrance service for the loved ones of patients who had passed away in the unit over the

## The Service

The service was planned by the multi-disciplinary palliative care quality improvement group. Funding to host the service was obtained from the charity To Absent Friends.

The critical care database, Ward Watcher was utilised to identify all patients who had passed away in the unit over the course of the pandemic. Importantly this included those who had passed as a direct consequence of COVID and those who had not. The total number was 237.

The families and loved ones of each patient were invited.

A non-denominational service consisting of readings, live music and acts of remembrance was held within the hospital grounds. It was attended by over 13 member of staff and over 40 families

## Feedback

Feedback was obtained from both staff and families who attended.

Staff who attended were asked to complete an online feedback form.

69% of those who attended completed the feedback and rated the service to be successful (0 being very unsuccessful and 10 being very successful)

How successful did you find the service?



The majority (89%) reported that it brought them comfort.

Did attending the service bring you comfort?



Formal feedback from families and loved ones who attended was limited. However, anecdotal feedback was positive. Examples include:

*"Heartfelt thanks to all for the service which gave me the 'closure' I did not get in 2020 with a COVID limited funeral"*

*"It was a lovely, albeit emotional, service which gave a lot of comfort to myself and my daughter"*

## Conclusions

Although the feedback received was limited, both formal and anecdotal feedback from attendees suggests a remembrance service can be of benefit to both families and staff, particularly in the context of a pandemic when visiting was curtailed.

# What matters to families



The lovely remembrance service helped my daughters and I as it went some way to replacing the service she did not have.

I just wanted to say thank you very much to everyone involved in arranging Saturday's Service of Remembrance. It was a lovely, albeit emotional, service which gave a lot of comfort to myself and my daughter. Then to sit and speak with other families whilst enjoying the delicious home-baking was the perfect way to end the morning.

Thank you for the lovely Remembrance Service. Everything was perfect and so fitting. My husband would have loved it too. Thank you to everybody for looking after him and my family are forever grateful to all the staff in those hard and difficult times.

# A sanctuary – HALO gardens and a buddy chair





good to talk  
over situations  
where I felt I  
could have done  
better. Dr Gray put  
my mind at rest.

It was good  
to know that  
Senior staff members  
were affected too  
and also required  
support.

I felt like  
it was easy to  
talk and be listened  
to. It was also good  
to hear how other people  
felt and taking into  
account the overall  
situation.

The session  
was confidential  
where I could discuss  
my feelings and fears  
without judgement  
and listen to  
those of others.

10:07 5G 55

← Tweet



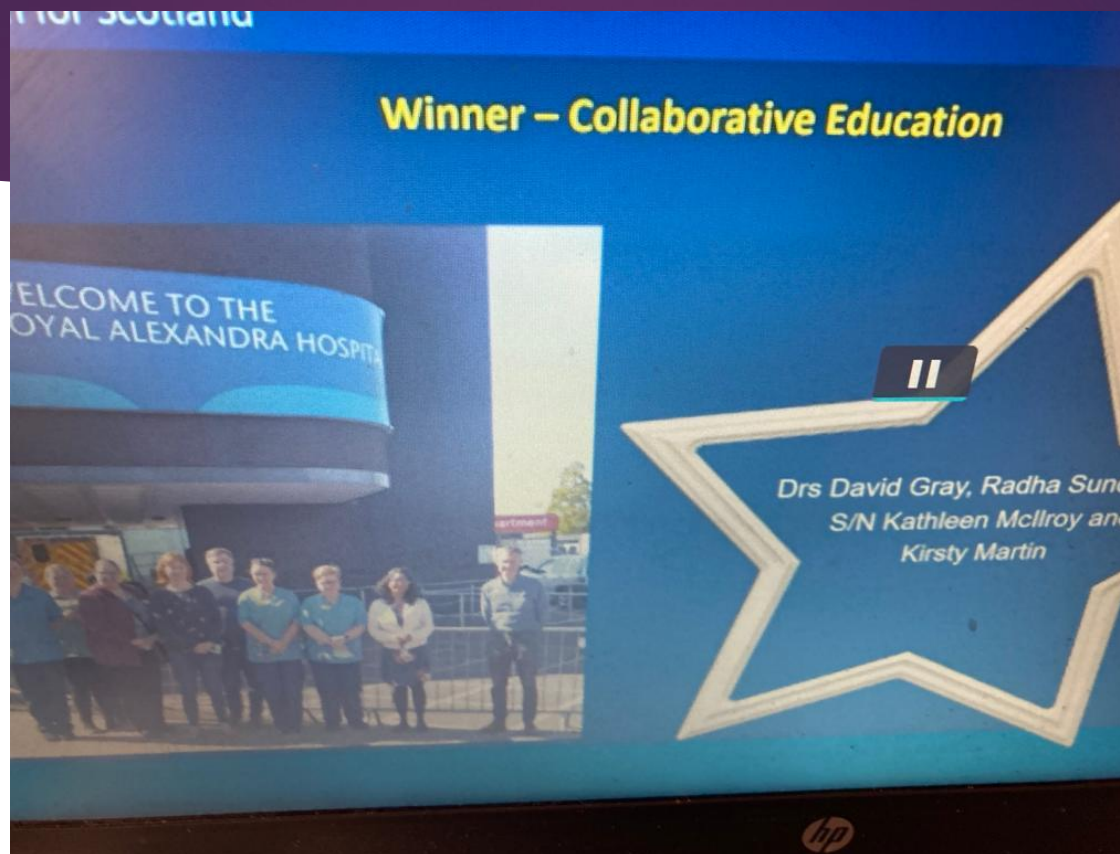
The End of Life Quality Improvement Group, Critical Care, at the Royal Alexandra Hospital in Paisley work so hard, and they're still putting on a memorial event for [#ToAbsentFriends](#) on November 26 [@nhsggc](#): [toabsentfriends.org.uk/news/festival-...](https://toabsentfriends.org.uk/news/festival-...)



11:47 · 03 Nov 22 · Twitter Web App

4 Retweets 6 Likes

Tweet your reply



# Service Evaluation

EOL Prescribing	Increased from 61% (2020) to 79% in 2022
Coffee and COMFRT	Three meetings a year since 2021 ; last meeting attended by 20 staff members
Keepsakes	Offered to every family at EOL
Organ Donation	Referrals have increased from 10 ( 2018) to 29 (2022) and donations from 2 to 6
Palliative care involvement	No data but sense that referrals are more frequent
Staff engagement	QI group has expanded from 5 members to 15
Professional Development	Three abstracts – two for doctors in training and one for nurses , two national meeting , one journal article in progress,



# Value Based Reflective Practice (VBRP)

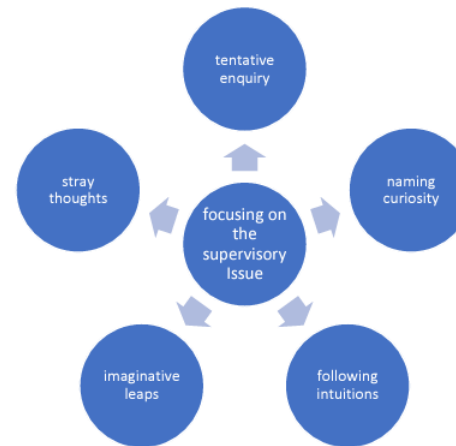
- ▶ VBRP® promotes person-centred care
- ▶ It engages in dialogue between personal and organisational values, attitudes and behaviours.
- ▶ It enhances staff fulfilment and turns history (what we have done) into learning.
- ▶ It supports staff members to better manage their own wellbeing and resilience, and helps them to develop increased reflexivity in their practice.
- ▶ The goal is to improve the care provided to patients and service users.
- ▶ Our spiritual leads (chaplains ) are trained in it and now participate in Coffee and COMFRT debriefs and clinical Multi disciplinary meetings

# VBRP®

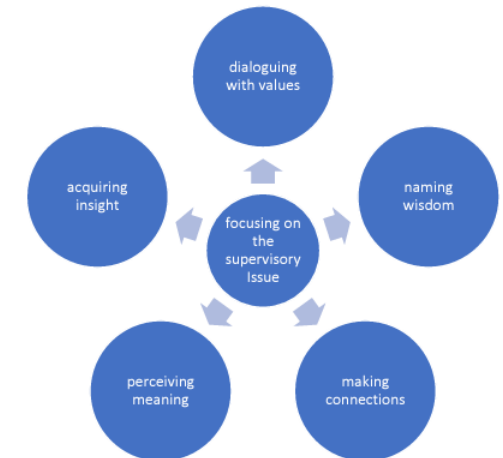
## 1<sup>st</sup> Level of Seeing – Seeing & Noticing



## 2<sup>nd</sup> Level of Seeing – Wondering & Musing



## 3<sup>rd</sup> Level of Seeing – Perceiving & Realising





# Evidence vs real world

TABLE 1. Elements of Intensive Care

Element
Nonabandonment <sup>4,6</sup>
Committed, quality connection
Ongoing support
Taking an interest in the patient as a person <sup>7,9</sup>
Enhance empathy, respect, connectedness
Affirm worth of who they are, were, or tried to be and what they achieved or tried to accomplish
Holding/containing hope <sup>10-15</sup>
Finding hope for psychological, spiritual, and physical comfort
Hope for minimal suffering and a peaceful death
Finding meaning and purpose in Relationships
Imparting words/sentiments that need to be shared, such as reconciliation, forgiveness, love, affirmation of feelings
Modeling how to die
Guiding families toward viable opportunities <sup>15</sup>
Time
Connection
Comfort
Forgiveness
Goodbyes
Dignity affirming tone of care/Therapeutic Presence <sup>16</sup>
Being compassionate and empathic
Being respectful and nonjudgmental
Being genuine and authentic
Being trustworthy
Being fully present
Valuing intrinsic worth of the patient
Being mindful of boundaries and being emotionally resilient
Therapeutic humility <sup>16</sup>
Tolerate clinical ambiguity
Accept and honor the patient's expertise
Trust in the process
Avoid the need to fix

## REALISTIC MEDICINE

CAN WE:



# Acknowledgements

EOL QI team at RAH

Prof Kevin Rooney Clinical Director

Dr David Gray Consultant in Palliative Care

To absent friends – Scottish charity

Aileen Labram Specialist Nurse in Organ Donation

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- ▶ 1. Values based reflective practice (VBRP®) | Turas | Learn (nhs.scot)
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- ▶ 3. Care at the End of Life | The Faculty of Intensive Care Medicine (ficm.ac.uk)
- ▶ 4. Palliative care in intensive care units: why, where, what, who, when, how | BMC Anesthesiology | Full Text (biomedcentral.com)

# Questions

You matter because you are you  
and you matter to the  
last moment of your life

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# Building capacity - to understand the patient and yourself

Christina Fogtmann, Professor , Københavns Universitet  
Charlotte Verner Rossing, Director Research and Development,  
Pharmakon, Danish College of Pharmacy Practice

Pharmakon



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## Pharmaceutical care

"The responsible provision of drug therapy for the purpose of achieving definite outcomes which improve the patient's quality of life."

Hepler og Strand 1990

## Kierkegaard

*If One Is Truly to Succeed in  
Leading a person to a  
Specific Place,*

*One must First and  
Foremost Take Care to Find  
Him Where He Is and Begin  
There*



# Patient-centered communication

To establish patient-centered communication patients need to engage their first person perspective

## **An important task of health care professionals:**

Relationship building wherein patients experience a genuine interest and curiosity

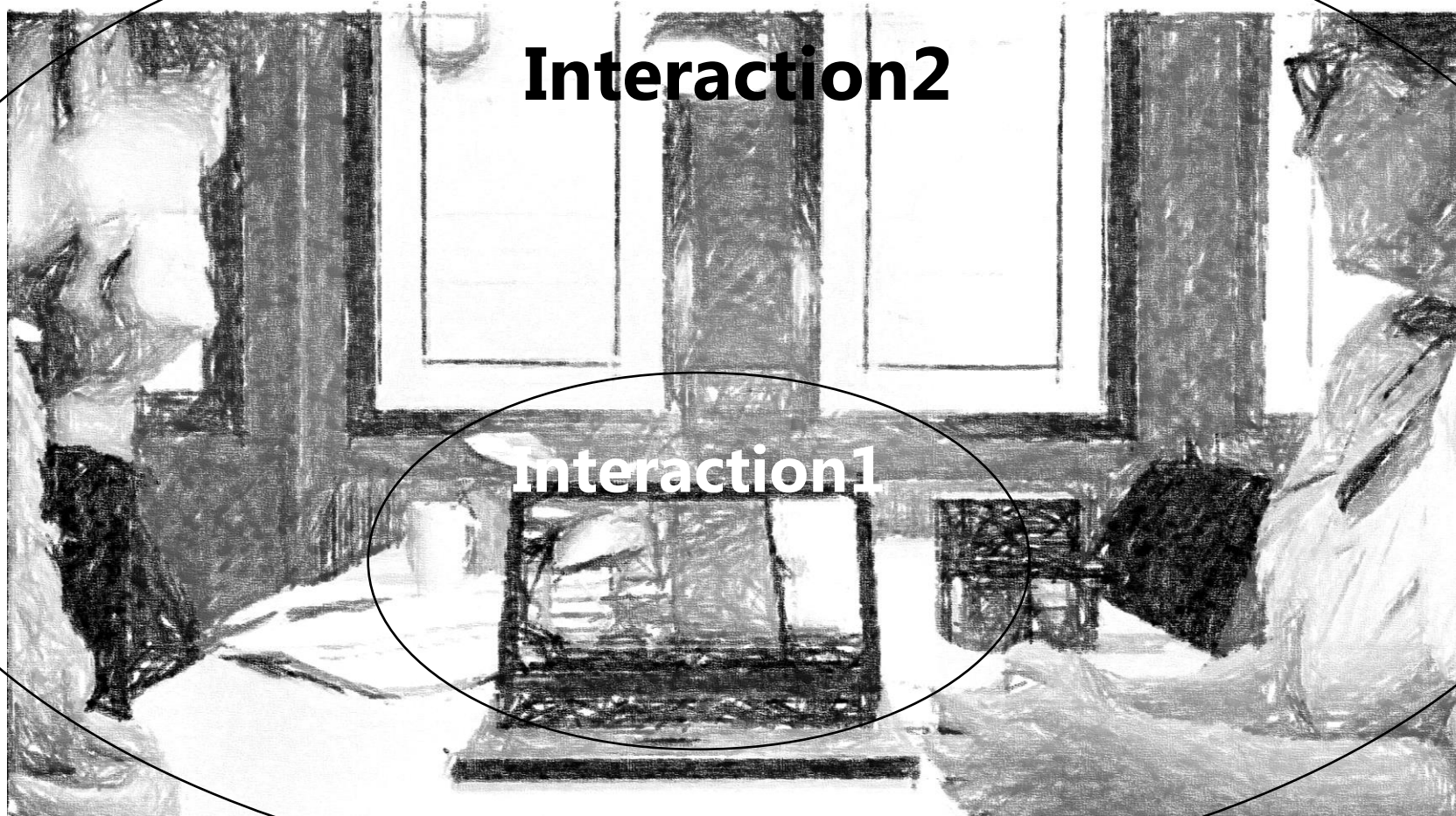
- Invite patients to engage their perspective - Responsiveness toward these perspectives

*A skill that needs to be professionalized*

This calls for staff to be inclined to understand the patient



# Video-stimulated recall interview





# Findings based on video-stimulated interviews



Patients are emotionally affected in ways which impact on their medication taking

When patients invest their personal perspectives, pharmacy staff sometimes withdraw from the counselling process



# What is mentalization?

- An activity involved with trying to understand the mental states connected to our own and others' behavior

Mental states: thoughts, feelings, needs, intentions

- Meeting others as unique individuals

With acceptance, interest and peace of mind

- Double-perspective

Mentalizing entails understanding both the other and understanding oneself

- Everyone is capable of mentalizing, but to varying degrees

The ability can be trained

## If the mentalizing ability is trained

- Attention to and understanding of customer reactions increases
- Attention to oneself, one's own reactions and barriers in customer meetings increases

Consequence: customers can be helped with their specific questions and challenges regarding their medicine

Fosgerau, C., Clemmensen, N. B., Husted, G. R., Kaae, S., & Rossing, C. (2022). PROGRAMME DESCRIPTION: A mentalising education programme for community pharmacy workforce. *Pharmacy Education*, 22(1), 77-87.

Mentalization has not previously been incorporated into pharmacy

But the tendency is apparent in other domains of healthcare interactions

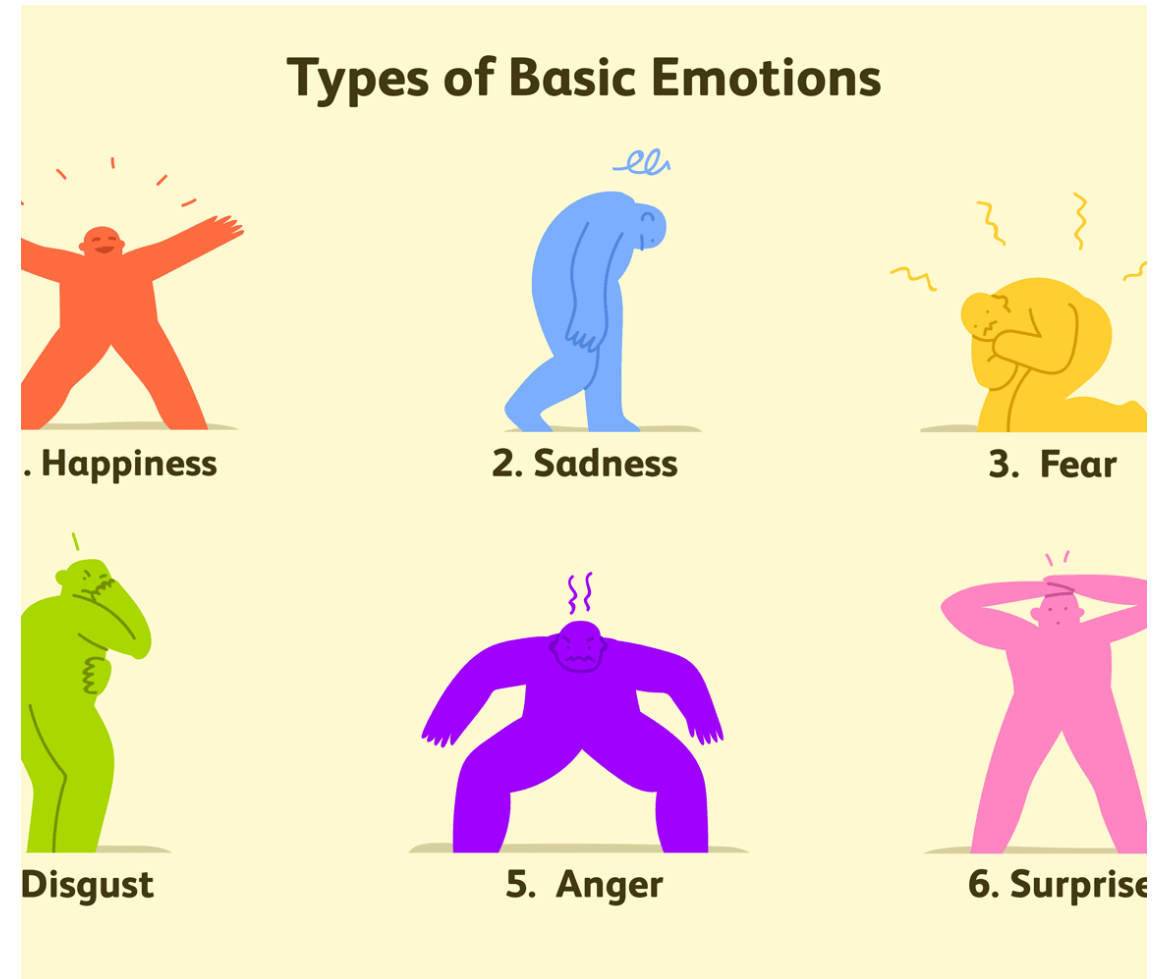
# Emotions

Originating in the body

Emotions add value to our experiences

Affect how we act in the world

We are always in an emotional state





# MENTALIZING AND EMOTIONAL AWARENESS



Emotional awareness:

The ability to identify and name other people's and own emotions

Central to emotional awareness is the ability to regulate emotions

# Counselling first hand - Understanding the patient and yourself through mentalizing

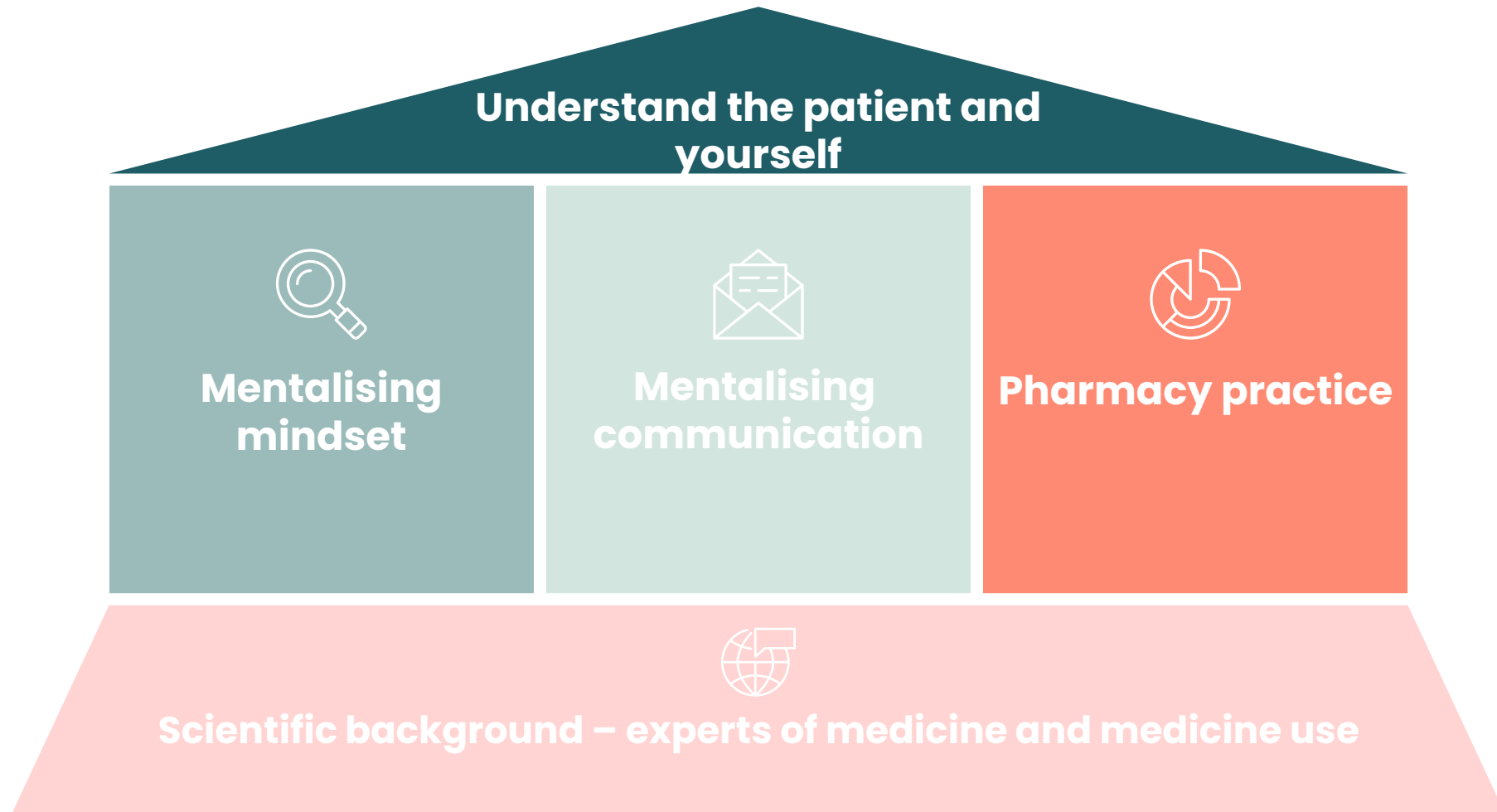
Tested in 2021

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# Two perceptions of pharmacy counselling

The scientific perception	The humanistic perception
Evidence-based, quality-controlled practice	Empowerment of the patient
Medical starting point	Starting point in everyday life
Expert role	Discussion partner
Objective (value neutral)	Personal, subjective (with values)
Focus on symptoms, medicine-related problems and lifestyle issues	Focus on the patient's experiences, wishes, beliefs, feelings and circumstances
Identifying risks, errors and problems	Identifying resources
Giving correct advice and recommending the right treatment	Tailor making solutions
Network involves a risk of noise and mistakes	Network is an important resource
The professional is in charge	The patient is in charge








- Classroom teaching
- Online teaching
- A new competence
  - Knowledge
  - Exercises
- Individual feedback
- Home assignments
- Final assignment

*Pharmacy Education* (2022) 22(1) 77 - 87  
<https://doi.org/10.46542/pe.2022.221.7787>



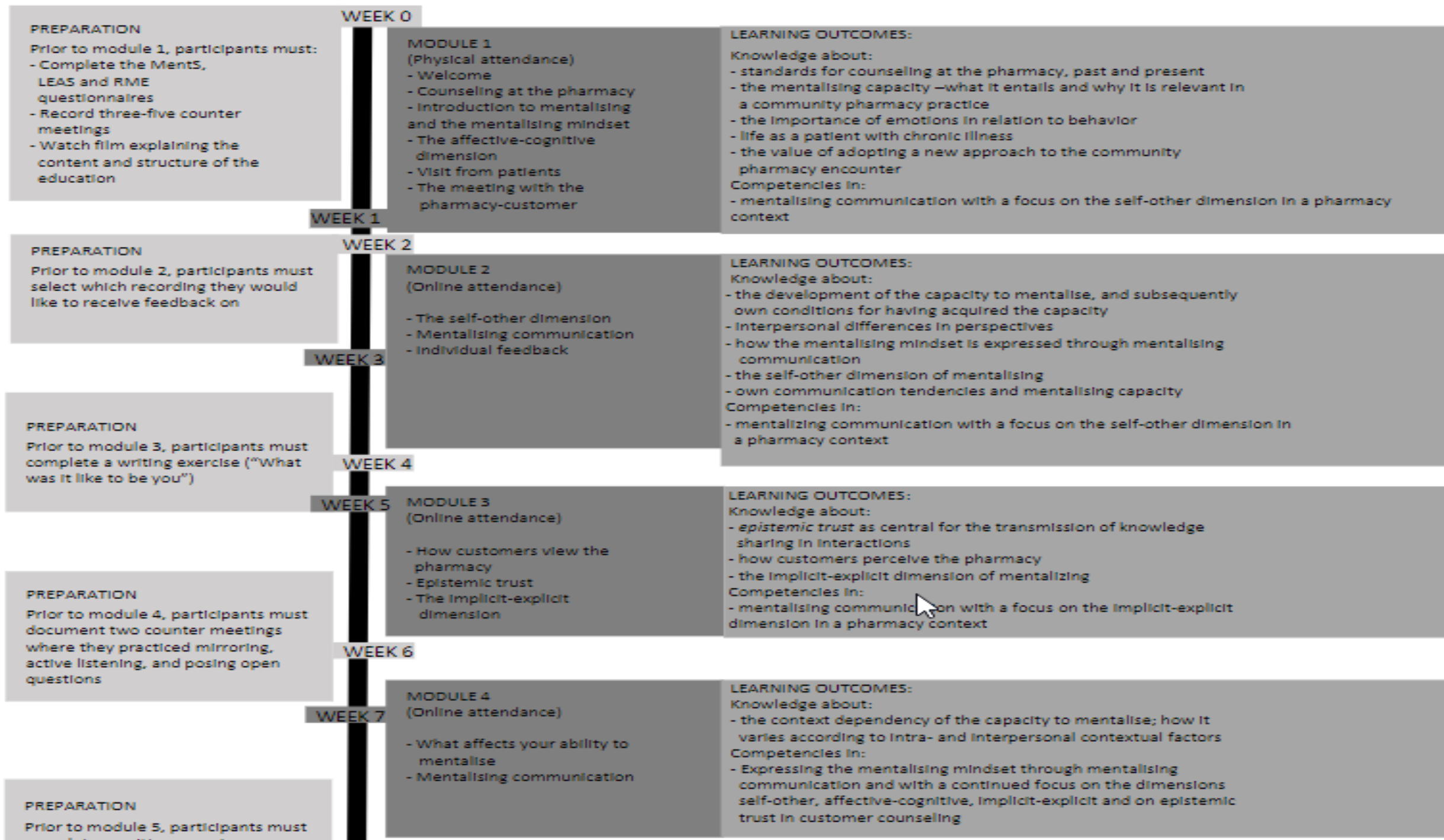
## PROGRAMME DESCRIPTION

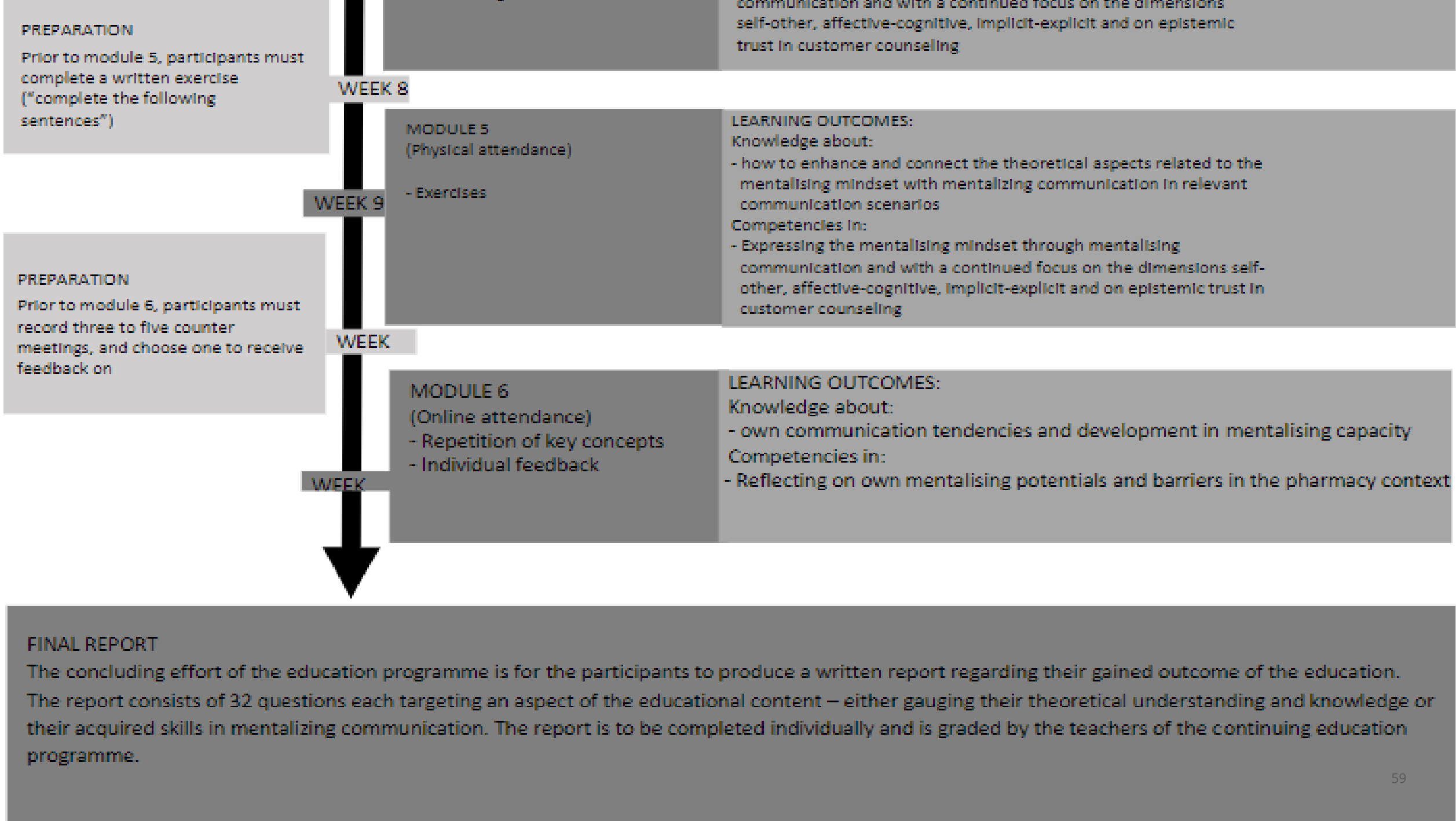
# A mentalising education programme for community pharmacy workforce

Christina Fosgerau<sup>1</sup> , Nanna Broch Clemmensen<sup>1</sup> , Gitte Reventlov Husted<sup>2</sup> , Susanne Kaae<sup>1</sup> ,  
Charlotte Rossing<sup>2</sup> 

<sup>1</sup> University of Copenhagen, Denmark

<sup>2</sup> Research and Development, Pharmakon - Danish College of Pharmacy Practice, Denmark





**– Promising results from the evaluation of an education programme for pharmacy workforce to support patient-centred counselling.**

Ph.D., MScN. Gitte Reventlov Husted, Pharmakon  
Co-authors: Rossing CV, Jacobsen R, Kaae S,  
Hedegaard U, Almasdottir AB, Fosgerau CF

**Pharmakon**



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## Purpose of the evaluation

- to evaluate participants' knowledge of mentalizing in a community pharmacy practice context and their skills and benefits of transferring this to knowledge about how to act and communicate in mentalizing ways in pharmacy encounters, with the potential of establishing patient-centred counselling.



## Quantitative results

- a significant increase in awareness of mental states ( $p < 0,001$ ),
- a significant improvement of job satisfaction regarding salary ( $p = 0.01$ ), prospects ( $p = 0.04$ ) and standards of care ( $p = 0,004$ ),
- that most participants agreed (47.8%) and strongly agreed (39.1%) that they were satisfied with the education programme.

## Qualitative results

Three themes

- 1) “Awareness of emotions and communication skills is an important element when mentalizing is the goal”,
- 2) “It’s far more than just a dispensing situation – I now tune into the patient”
- 3) “Don’t have to hide behind the screen any longer”.

## In conclusion

*"Every day, I try to meet all patients with interest, serenity and acceptance. That's given me a lot of eye-opening experiences and many more positive and successful counselling situations – situations where I believe I've made a difference for the patient – for the sake of the patient – and where I've also had a positive experience of the interaction with the patient myself. It's become much more than a dispensing situation."*

*"My awareness of the patient has been strengthened. I'm much more aware of signals from the patients who express their emotions verbally and non-verbally. At the same time, I've become aware of my own emotions, thoughts, needs and intentions. I know now that I have to be able to embrace the patients' emotions and thoughts as well as my own."*



## References

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