

# **CHILDREN WITH COMPLEX HEALTH NEEDS: THE EXPERIENCE OF SIBLINGS**

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# AIMS AND OBJECTIVES

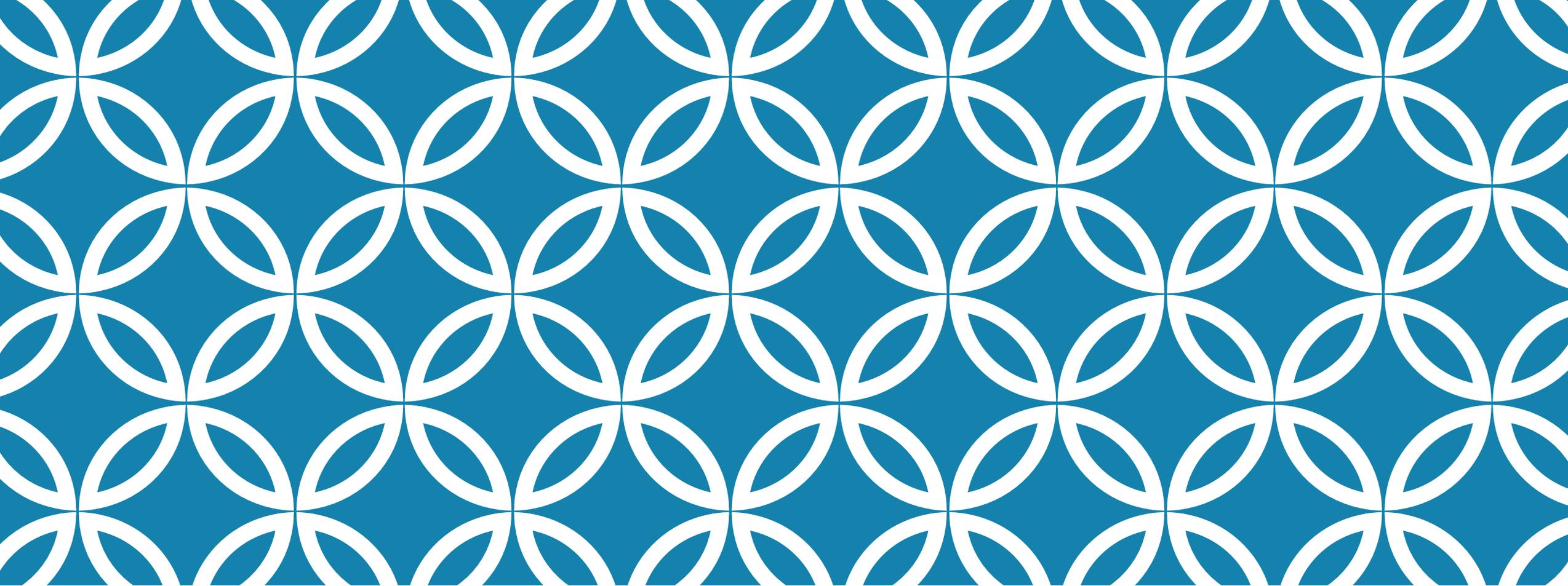
- ❑ To explore the experiences' of siblings growing up with a child with complex health needs
- ❑ To explore siblings experiences of helping to care for their sibling with complex health needs
- ❑ To explore coping mechanisms available to siblings and family experiences
- ❑ To explore future interventions and services that may help to improve the quality of family life for siblings
- ❑ To identify future research opportunities and gaps in the literature

# BACKGROUND

- ❑ Children with complex health needs are children requiring significant health care input due to one or more conditions, with functional limitations that often require technology assistance or multiple health support services (Brenner et al. 2015).
- ❑ Ling et al. (2015) estimates that there are 3840 children living with a life limiting condition in Ireland based on UK figures.
- ❑ Few papers look at siblings of children with complex need encompassing life limiting and life threatening conditions or illnesses

# METHODS

- A systematic review of the literature was completed ranging between 2007-2018. 674 articles were identified, a final number of 9 were included in the review. These were agreed on with my dissertation supervisor Patricia Mc Neilly QUB.
- Screening was completed using critical appraisal methods.
- Three emerging themes were identified and the data grouped together and synthesised. A total of nine studies were reviewed.
- Three of the studies had parental proxy
- Two studies were qualitative, 2 quantitative and 5 studies utilised mixed methods.



# FINDINGS



# THEMES

□ On analysis of the data collected three main themes emerged;

1. Emotional Experiences
2. Coping Strategies and Support
3. Family Life

# EMOTIONAL EXPERIENCES

- The relationship between siblings is unique and special

Positive Emotions	Negative Emotions
Happiness	Fear
Pride	Resentment
Protective instinct	Jealousy
Love	Anxiety
Joy	guilt
Want to help out	

- Quantitative findings: according to Fullerton and Giallo, most siblings do not develop clinically significant levels of emotional and behavioural problems despite extra demands being placed on them within the family according to SDQ scores

# COPING STRATEGIES AND SUPPORT

- ❑ Active Vs. Passive Coping
- ❑ Need for communication
- ❑ Support groups- Availability – wanted to belong to a group that understood- need for hospice link
- ❑ Quantitative results
- ❑ Need for time out even for parents (Velleman et al. 2016)

# FAMILY LIFE

- ❑ Changes to normal home environment
- ❑ Disease trajectory
- ❑ Lack of attention
- ❑ Frustration, resentment, financial difficulties
- ❑ Different rules for sick child
- ❑ Family time

# STRENGTHS AND LIMITATIONS

Strengths	Limitations
<p>Specific to complex needs children</p> <p>Both quantitative and qualitative literature reviewed</p> <p>International perspective examined</p>	<p>Data synthesised from previous research</p> <p>All English language journals therefore data may have been missed</p> <p>Some sampling bias as many participants were already linked in with hospice services</p>

# FUTURE RESEARCH

- Need for more longitudinal studies
- Study related to services in Ireland
- Need for more support groups
- Awareness of social inclusion

# CONCLUSION

- ❑ Irish healthcare does not as yet recognise siblings as stakeholders in the care for children with complex needs
- ❑ Improvement is evident
- ❑ Still a need to increase awareness

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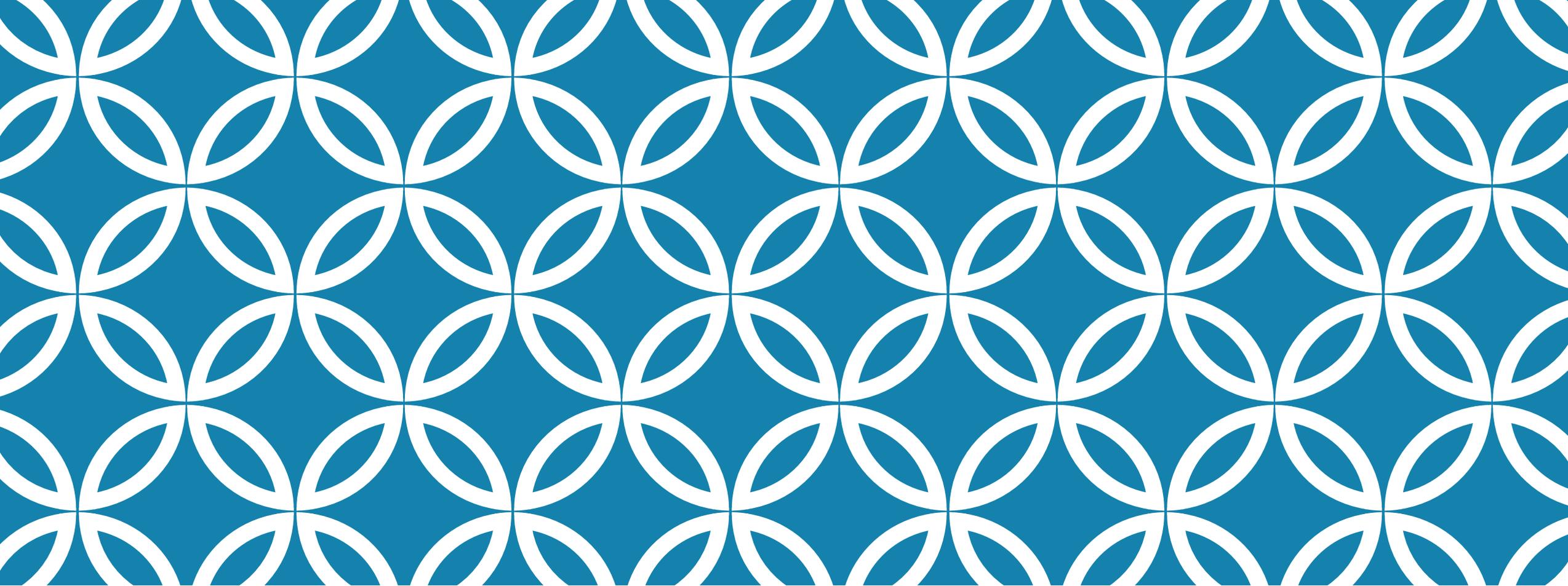
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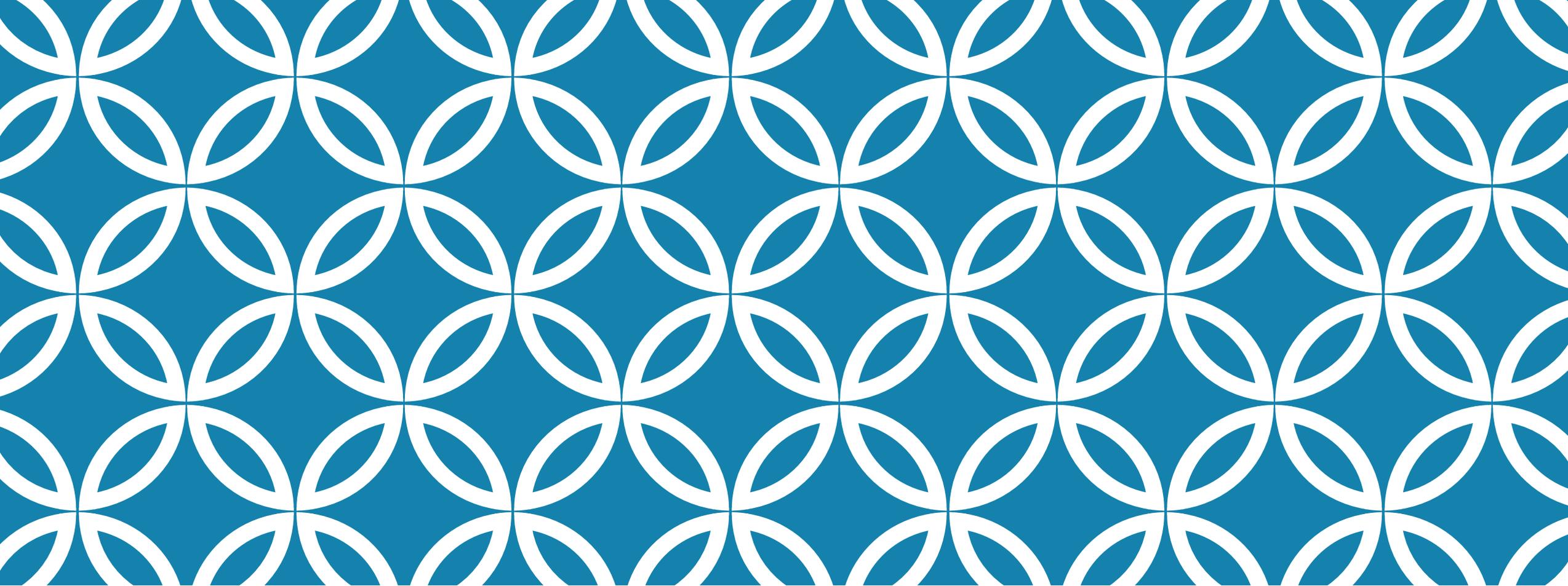
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**THANK YOU FOR LISTENING** |



# QUESTIONS

