



The Lived Experience of Volunteer-Supported Palliative Care

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Isle of Man (IOM)



Ageing Population (oldest old)

- Effects of an ageing population
- IOM in Global Ranking
- Palliative Care Planning
- Compassionate Communities through Volunteering

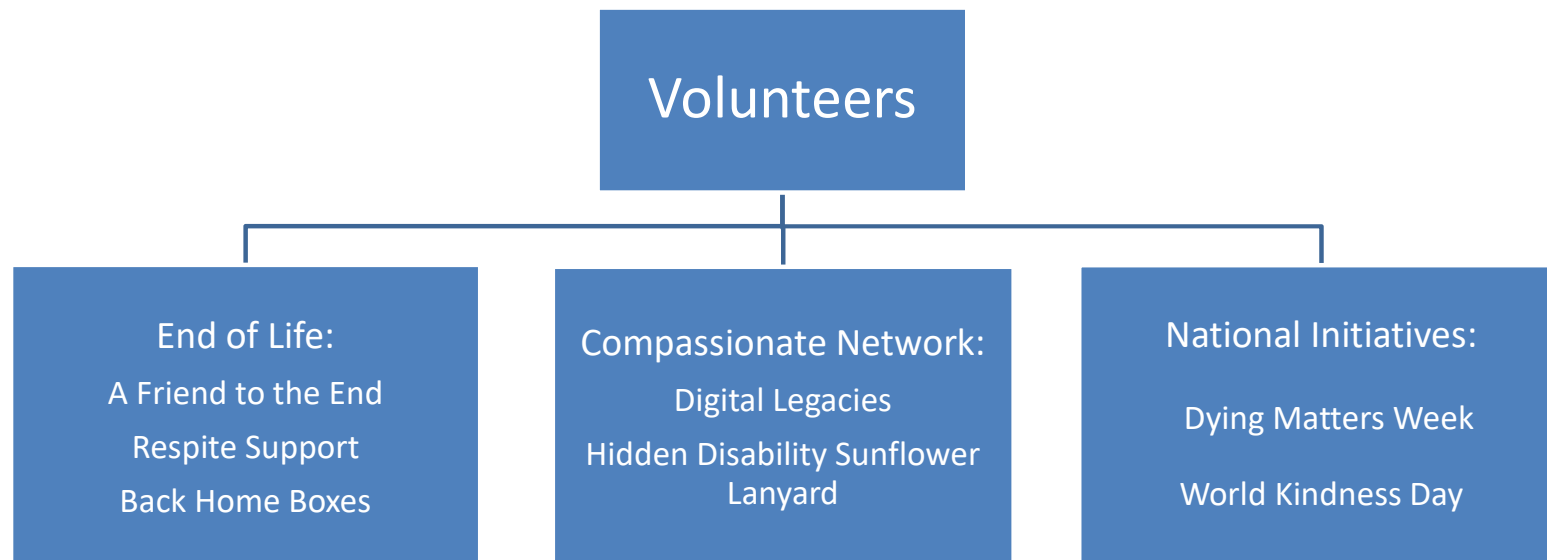
%age Population over 64

1. Japan	28.40
2. Italy	23.30
3. Portugal	22.77
4. Finland	22.55
5. Greece →	22.28
6. Germany	21.69

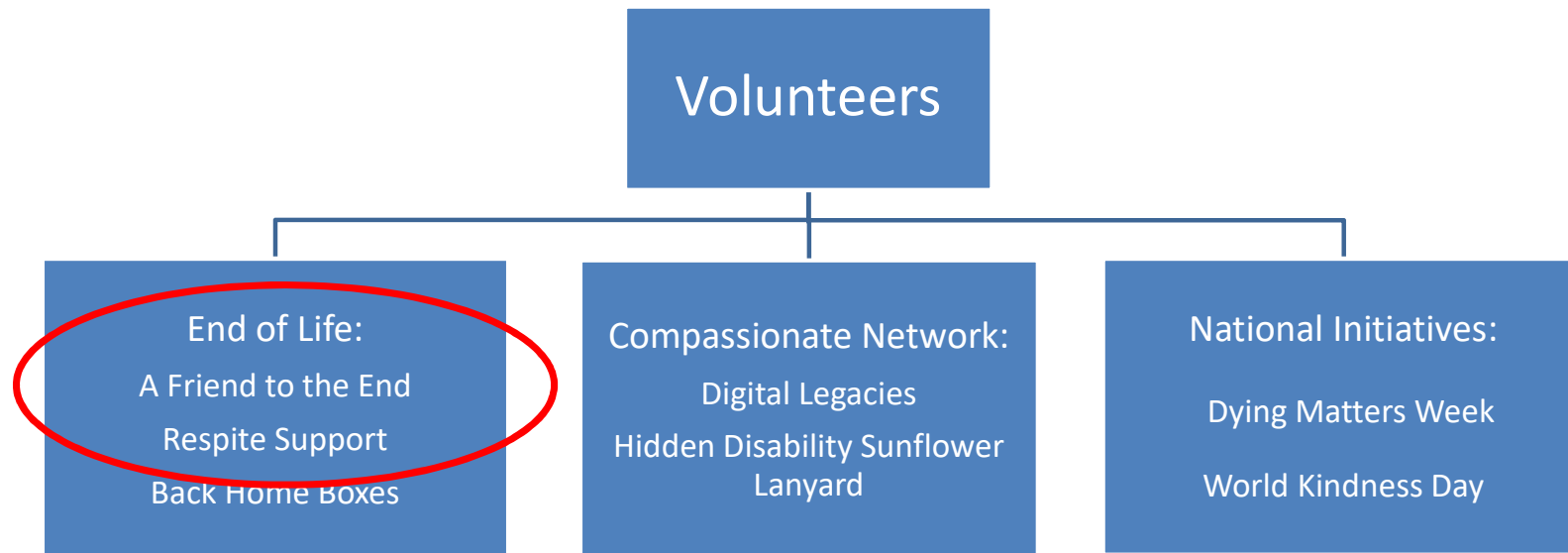
Stats https://www.theglobaleconomy.com/rankings/elderly_population/

<https://www.gov.im/media/1356108/schools-nor-sep2020.pdf>

Compassionate IOM (CIOM): Current model



Compassionate IOM (CIOM): Current model



Both programmes dependent on volunteers

Started from scratch in 2018 with adverts for interested volunteers

Volunteers' Experiences (theory)

- Two types of input:
 - ‘being there’
 - ‘doing for’ (Dodd et al, 2018)
- Volunteer roles:
 - ‘mediating between patients and staff’
 - ‘acting as a surrogate family member’ (Burbeck et al, 2014)
- Need for more detailed information about impact on recipients and volunteers
 - Assist training and development of volunteers
 - Inform deployment of volunteers



Steps in CIOM Volunteer Development

- Develop and test a training package to support volunteers to act as carers
- Evaluate impact of volunteering on the volunteers
- Evaluate the impact of the programme on care recipients

- Some early findings

Training Programme

- Information Technology
- Safeguarding
- End of Life processes
- Staying safe
- Listening skills
- Dementia care
- No moving and handling



Evaluation of Training Programme

- Specially-designed questionnaire
 - Most/least beneficial aspects
 - Suggestions for improvement
 - Relevance to needs
 - Confidence in skills learned
 - Performance of instructors
- Results very positive
 - Course overwhelmingly met perceived needs and increased confidence
 - De-briefing sessions requested



Impact on Volunteers

- Why did you volunteer and what do you expect?
- Current/follow-up wellbeing measure (SF-6D)
- Current/follow-up feelings of agency (specially designed questions)
 - At start of training and after eighteen months
- De-briefing sessions to capture volunteers' experience
- Testing of role of capability measure (ICECAP A)



Early Findings - Volunteers' Demographic

- Volunteer Characteristics
 - all female
 - ages range 52 to 75, average age 63
- Background Professions Breakdown (19 volunteer sample)
 - clinical 4
 - other health professional 3
 - education 3
 - business 7
 - none 2

Early Findings - Volunteers' Motivation

Ranking of Reasons for Volunteering

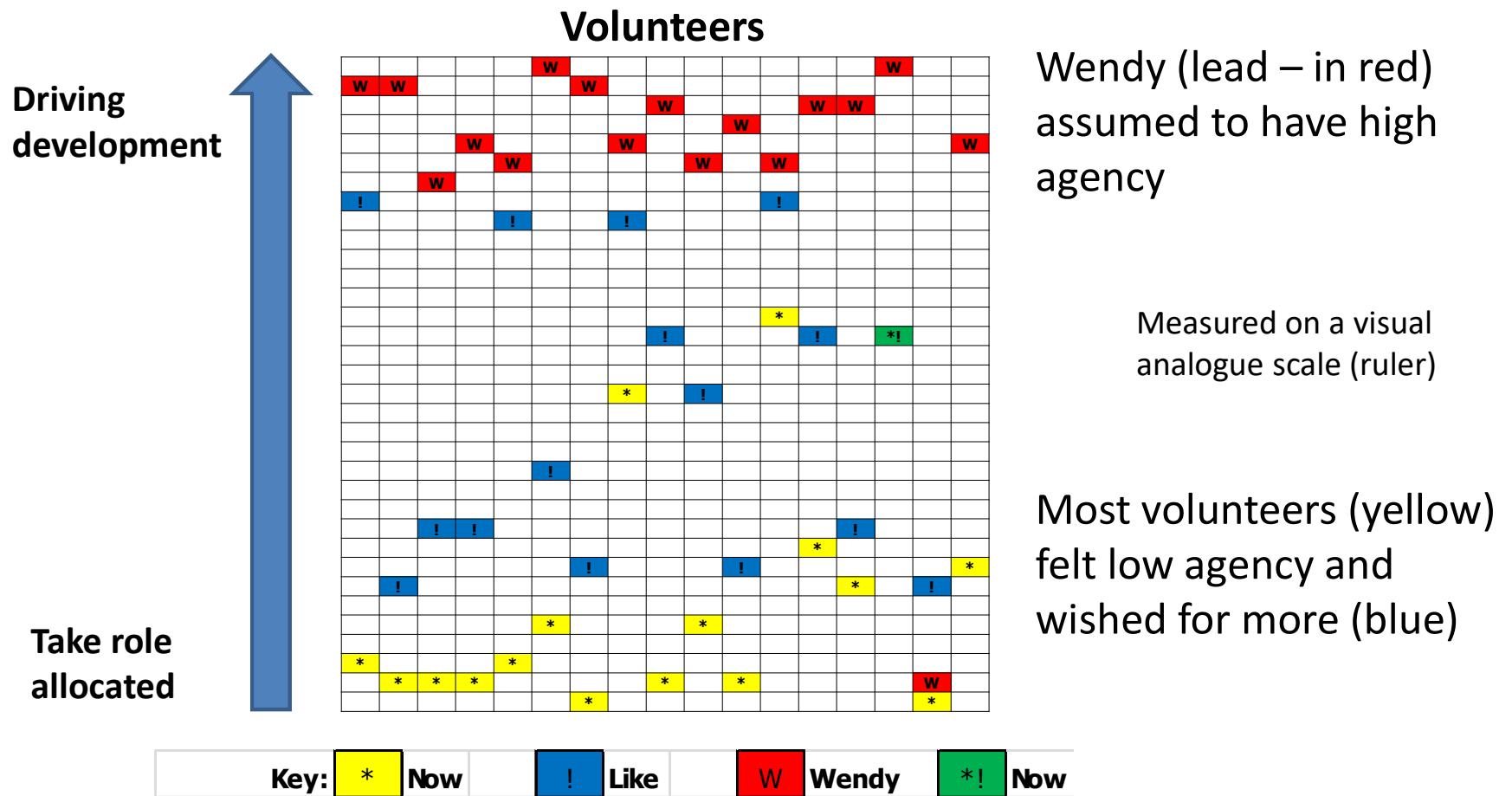
1. help others
2. personal wellbeing
3. meet people
4. learn skills
5. new experience
6. promote compassion
7. share own experience
8. support hospice
9. be part of CIOM



Other Findings

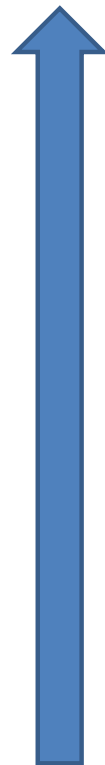
- Dropout low
- Group bonded – coffee & chat sessions
- Drip feed approach to training highly appreciated

Desired Role in the Project at Baseline



....after 18 months

Driving development



Take role allocated

Volunteers

W2			I2	*2	
W			W2		
		W			W
	W2	W2			
			W		W2
	W				
			!		
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I2		!	*2		
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Results of 6 with follow-up data (so far)

All have moved from baseline (yellow) to higher (orange) agency

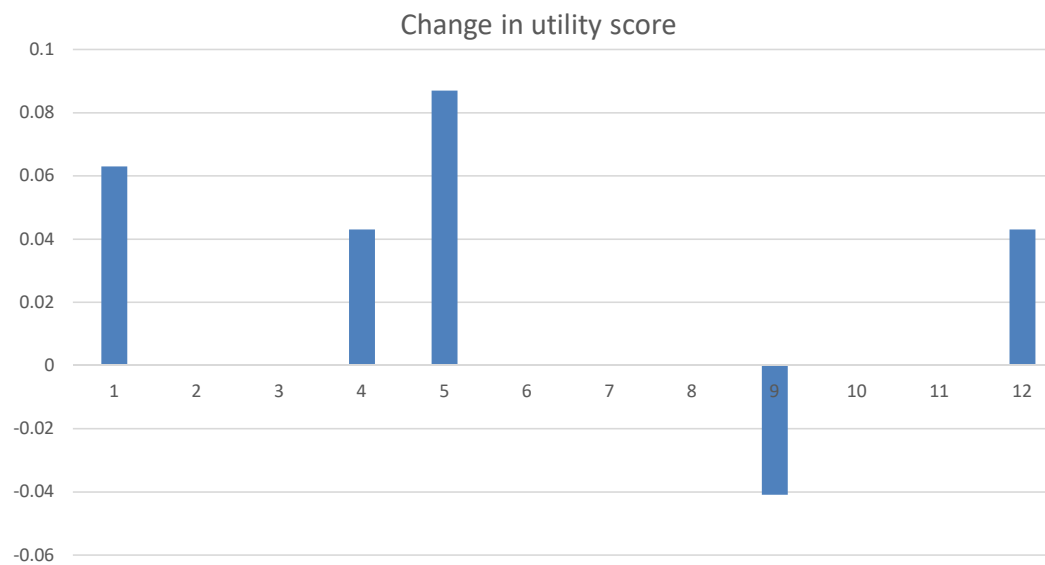
Most want to gain even higher (purple) agency

Two (green) have reached the level they want

1 wants to and 1 has surpassed the lead



Some Early Findings on Volunteers' Wellbeing



Average change in quality of life during study period = + 0.04 on scale of 0 to 1

If maintained over, say, 5 years = $0.04 \times 5 = 0.2$ QALYs gained through volunteer work

Other Unexpected Benefits

- Supported Hospice staff e.g. at night
- Volunteers learned about Hospice services – information into community
- Social network development for volunteers
- While able to hand over other services e.g. BHB to Foodbank, World Kindness to a mental health charity, volunteer services need training, support and links with services
- ICECAP A unable to monitor improvements in volunteer wellbeing because volunteers scored maximum at start



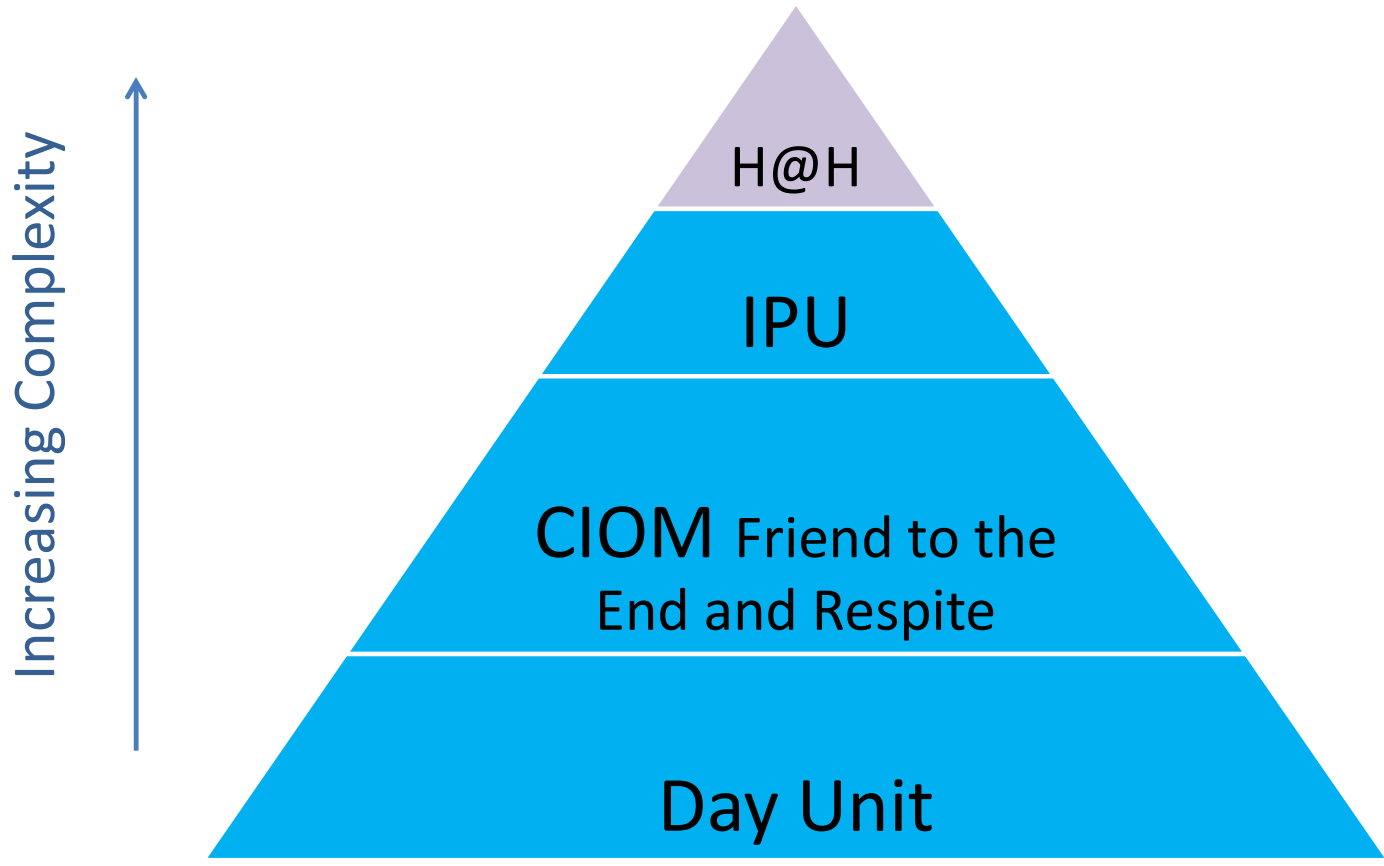
Volunteer Comments from De-Briefs

- The work was a privilege
- A humbling, great experience
- Staff attitudes to volunteers improved
- The more you do the more you want to do
- Thought I would be driving only but ended up giving support
- Grows one's confidence
- Dementia training would be helpful, drip-feeding and mouth cleaning training were useful
- Sometimes I feel I can't but then I do it and it's positive

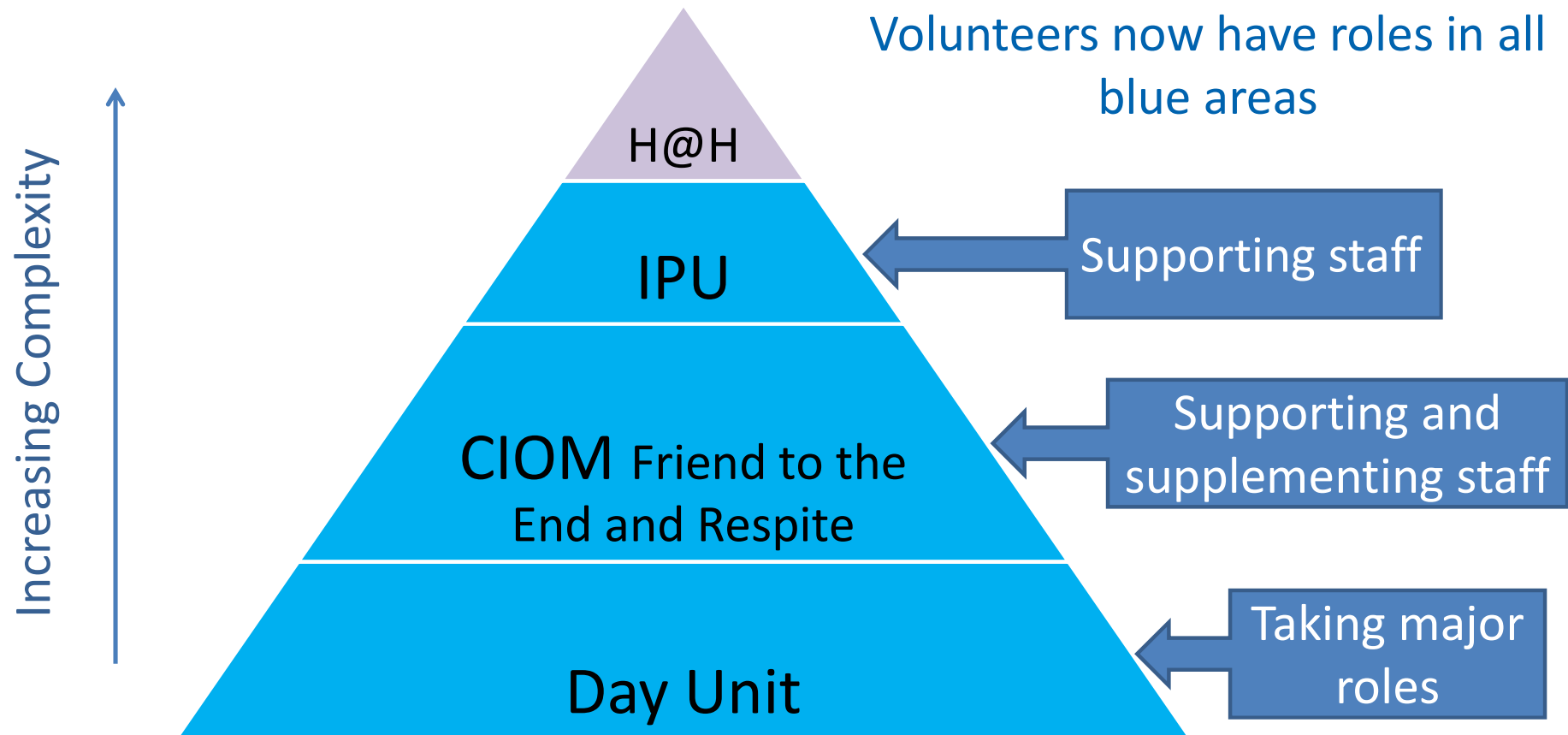
Impact on Care Recipients

- Capability measures
 - Testing of ICECAP A, ICECAP O, Carers experience scale
- Specially-designed satisfaction questionnaire
- Results to date:
 - ICECAP O seems better, A gives same results but more difficult to answer
 - CES useful – all carers really needed respite support
 - Satisfaction high

Matching Volunteer Roles to Patient Needs and Hospice Services



Integrating Volunteers



THANK YOU

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