A simulated online clinical ethics committee

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In Adolescent / Young Adult Cancer Care

‘In-betweeners’- a crucial life stage
1% total cancer population
AYA have unique needs
Health workers need to know about these

TYA or AYA?
Educating the AYA Cancer Workforce

Interprofessional – who is involved?

International

E-learning

Curriculum development
# Post Graduate Certificate in TYA Cancer

<table>
<thead>
<tr>
<th>Term 1</th>
<th>Term 2</th>
<th>Term 3</th>
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</thead>
<tbody>
<tr>
<td>The Developing Teenager/Young Adult with Cancer</td>
<td>Care of the Teenager/Young Adult with Cancer</td>
<td>Independent Study</td>
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## Course Aims

1. Demonstrate a systematic understanding of knowledge and critical awareness of issues of care in the care of Teenagers and Young adults with Cancer
2. Demonstrate a comprehensive knowledge of advanced techniques, using reflexivity to their advanced scholarship in this field of care
3. Demonstrate originality in their application of knowledge and interpretation of research in the field
4. Demonstrate conceptual understanding that enables the student to evaluate advanced scholarship on teenage cancer care and where appropriate to propose new hypotheses.
5. Facilitate continued professional development this field of care.

**Ethical principles and practice underpins all of this.**
ETHICS - thinking from a practitioner perspective

Underpins all professional codes of practice for those that are regulated

More than moral judgement or getting approval for a research study

Sometimes its hard to see and feel ‘ethics’

What does it mean to you?
Biomedical Ethical Principles & Frameworks

Justice, Autonomy, Beneficence, Non-maleficence

Four Quadrants (Jonsen et al, 1992) - medical indications, pt preferences, quality of life, contextual features

CARE model (Schneider and Snell, 2000) – core beliefs, how acted in past, reasoned opinions of others, experience

Good Clinical Practice

Codes of conduct

Research Governance Frameworks Such as IRAS

It’s ethereal and underpins everything we do but

how do we learn it?
disruption
TECHNOLOGY

DISRUPTIVE LEARNING THROUGH TECHNOLOGY
Disruption- a VE+ OR VE- thing in education?

New technologies ..are either sustaining or disruptive to an industry group. A sustaining technology enables an industry to improve existing products. A disruptive technology plays a more dramatic role. (Clayton Christensen 1997)

E-Learning makes non-linear learning strategies possible by which students are guided through learning materials that they do in their own time, often asynchronously.

Interprofessional education occurs when students from two or more professions learn about, from and with each other to enable effective collaboration and improve health outcomes. (WHO 2010)
Our Course

Delivered electronically  ✔
Interprofessional  ✔
Regulated and non regulated professionals  ✔
International  ✔
Ripe for disruption  ✔

Just like teenagers!
Q- But can we disrupt when learning ethics?

A- YES

How?

By running a SYNCHRONOUS virtual Clinical Ethics committee.
- Chaired by a chair of a real ethics committee
- Preceded by 2 lectures on Ethical Principles & a podcast from Inside the Ethics Chair
- CEC was recorded for reflection.
- Discussion posts invited online.
Our CEC & its evaluation

5 year track history of delivery – we present findings from 2

We have ethical approval to share this data which reflects student and teacher experience.
Clinical Ethics Committee

CECs have an important role to play in helping health care professionals and others address ethical dilemmas.

A wide variety of people sit on CEC’s. The majority of members have a medical or nursing background but more than half of the CEC’s we surveyed also have a legal member, lay and religious representation. (UKCEN, 2019)

Committees have varied functions:
- 54% frequently contribute to Trust policies and guidelines
- 20% frequently interpret national guidelines
- 37% frequently provide ethical education within the Trust
- 66% frequently provide ethical support to clinicians

Most meet monthly.
The Case - Freddie

24yr male, adopted, with Downs Syndrome & Acute Lymphoblastic Leukaemia. Being treated with curative intent on routine protocol - intensive++ for 2 years. Supportive family.

Needs frequent anaesthetic/sedation for treatments - long hospital stays.

6 months into treatment, he is depressed, distressed & wants to go home. Unable to conceptualise benefits of treatment.

Family concerned about his ability to tolerate remaining treatment.
The Mock CEC- AKA “the Disruption”

Chaired formally by Laura Strumidlo and lasts for one hour. Afterwards students are asked to post their reflections in a discussion forum.
Evaluation methodology

Ethics committee approval.

Purposive sample taken from x2 cohorts (cohort 1 n=10, cohort 2 n=12)

Data Collection method - Bristol Online Survey on usefulness of the CEC and impact of the experience on their perceived knowledge and understanding.

12 participants responded to BOS
### Findings

#### Student type

<table>
<thead>
<tr>
<th>Student type</th>
<th>Numbers</th>
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<tbody>
<tr>
<td>Nurse Consultant</td>
<td>1</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td>6</td>
</tr>
<tr>
<td>Staff Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
</tr>
<tr>
<td>Research Nurse</td>
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#### Place of work

<table>
<thead>
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<tr>
<td>Principal Treatment Centre for TYA with cancer</td>
<td>8</td>
</tr>
<tr>
<td>Designated Centre</td>
<td>3</td>
</tr>
<tr>
<td>Paediatric shared care</td>
<td>1</td>
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#### Yrs. of TYAC experience

<table>
<thead>
<tr>
<th>Yrs. of TYAC experience</th>
<th>Numbers</th>
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<tbody>
<tr>
<td>0-4</td>
<td>87</td>
</tr>
<tr>
<td>5-9</td>
<td>2</td>
</tr>
<tr>
<td>10-14</td>
<td>1</td>
</tr>
<tr>
<td>15-19</td>
<td>1</td>
</tr>
<tr>
<td>20+</td>
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#### Previous experience of participating in CEC?

<table>
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<th>Previous experience of participating in CEC?</th>
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<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
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#### Value of pre CEC learning materials

<table>
<thead>
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<th>Value of pre CEC learning materials</th>
<th>Numbers</th>
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<tbody>
<tr>
<td>Good</td>
<td>5</td>
</tr>
<tr>
<td>Excellent</td>
<td>17</td>
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1. Taking on another role

This was challenging for me as I would normally shy away from role play. To take on a different role was really interesting and allowed me to focus more in-depth on their viewpoint. Then I was able to learn from what others were contributing.....
2. Influence on students practice

It has helped me appreciate there is not always a clear 'right' answer when making decisions. It has given me confidence in contributing to MDT discussions about patient choice based upon personal values.

Awareness of diverse perspectives. The importance the roles we occupy have on influencing our perspectives and the importance to ask difficult questions of pre conceived views.
3. The authenticity of the CEC chair

It was the best part of the learning experience.....

This was valuable and most appreciated- it made it feel real

I did feel safe assuming the role - there was a very non-judgemental attitude from all participating.
Usability and acceptability as a teaching tool

I recommend this because I learned how to get help in deciding what to do and learned how to come to best consensus/outcome for the patient.

It's inclusive and a dynamic way of learning. Helps you feel part of the learning experience alongside peers and tutors.

I like anything that involved meeting and talking with others. Online learning can be lonely at times.
Discussion

1. We appear to have disrupted student learning & challenged thinking through the application of situated decision making.
2. Challenged unconscious bias.
3. The experience of the Chair enhanced learning and made it an authentic experience.
4. There is evidence of enhanced learning about the role and function of CEC.
5. Conscious of the need to create safe space to facilitate this.
6. The blend of synchronous and asynchronous learning works here.
7. Technology DISRUPTS & ENHANCES learning but it can also stop it if it doesn’t work.
8. This takes team effort- shared effort and shared decision making.
Acknowledgements

Students/Participants
Chair of CEC
Module tutors
Imran Ali - learning technologist
Laura Strumidlo and Debbie Critoph - both not here today
References


UK Clinical Ethics Network [http://www.ukcen.net/ethical_issues/ethical_frameworks](http://www.ukcen.net/ethical_issues/ethical_frameworks)