Development of an online ethics resource to foster situated ethical decision making:

Results of a Genethics Forum co-design project

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Ethical issues in Genetic Medicine

Arise when conflicting moral commitments suggest courses of action at odds with each other

- Rapid technological advances
  - How we interpret meaning from data may lag behind technology
- Familial nature of genetic medicine

Sharing of information

Feedback of findings

Reproductive decision-making

Genetic testing in children

Consent

Clinical-research overlap

Implications of genomics initiatives: practice/society

Ethical decision-making

Moral sensitivity	Identify issues Describe in **context**
Ethical reasoning	Ethical principles Analyse, reason and evaluate issues within context Reflect on options
Decision	

No ‘off-the-shelf’ answers

Guidelines/laws can be helpful – encourage moral behaviour

- Lack nuance & context
- Can encourage a regulatory approach to decision-making
- Doesn’t necessarily translate to good ethical decision-making in practice
- Examples from research practice:
  - ‘got’ ethical approval?

Royal College of Physicians | The Royal College of Pathologists Pathology: the science behind the cure | BSGM The British Society for Genetic Medicine

Consent and confidentiality in genomic medicine

Guidance on the use of genetic and genomic information in the clinic

3rd edition, July 2019

Ethical Preparedness

"a state from which one is able to identify and articulate ethical issues in a timely and ongoing manner, and where (ideally) one has the tools and the skills/experience available to address them"

- Foster ethical debate in advance of developments of healthcare
- Continue debate of challenging aspects of established practice
- Recognises limits of governance frameworks
- Seeks to develop & embed situated ethical decision-making skills within individual practitioners
- Backdrop of structural & organisational support

Process of ethical decision-making – analysis, reasoning & judgement - itself is of importance

Confidence to apply skills to variety of clinical situations

(Farsides & Lucassen, 2023)

Ethics support is important

Apply knowledge of principles into practice

Societal values evolve over time

Healthcare innovations can bring new ethical issues

- New doctors feel underprepared for ethical decision-making
- Postgraduate training in ethics overlooked
- Lack of investment in ethics support

NCOB report (2023) recognised need for ‘gold-standard’ model of ethics in genomics:

- Ethical principles, discussion fora, professional guidance & practical ethics tools

Clinical Ethics Support Services

Type	Format	Goals	Approach
Clinical Ethics Consultation	Request-based formal consultation by an ‘expert’ or group of experts	Clarify ethical issues Improve decision-making Address conflict between stakeholders	Top-down
Clinical Ethics Committees	Request-based formal review by a committee	Analysis of ethical issues in clinical/research practice Guidance and decision-making support on individual cases Development or review of policies, guidelines and protocols Education role	
Moral case deliberation	Discussion and reflection by a group of HCPs on moral issues relating to their clinical practice Facilitator-led, using theory-based conversation methods (e.g., Dilemma or Socratic Dialogue)	Support HCPs to navigate ethically challenging cases Help understand perspective of others Promote HCP reflection of ethical issues in practice as a way of developing EDM skills	Bottom up
Ethics Rounds / Discussion Groups / Reflection Groups	Discussion by group of HCPs from the same or different areas of practice Discuss challenging ethical issues relating to clinical cases, daily practice or institutional issues Facilitator-led		

Provision of practical ethics support and an ethics research laboratory since 2001
  - Thrice yearly, ~70 meetings
  - Discussion of challenging cases (1000+ presented formally)

Offers specific experience in ethical issues in genetics
- Goes beyond solution-finding
- Encourages **process** of ethical decision making (EDM)
- Empower healthcare professionals to develop a reflexive and situated approach to EDM

Efficacy hard to measure but recent online meeting had 157 attendees, 260+ on mailing list

Currently no way to learn from collective experience of Genethics meetings

Genethics organisers regularly contacted between meetings with requests to discuss urgent cases

How can we foster situated ethical decision-making in Clinical Genetic practice?

Online ethics resource?

Aims, objectives and research questions

Aims:	• To work with a group of Genethics forum participants to **explore the EDM experiences** of a diverse range of healthcare professionals and **to explore their views on developing a resource** to support future EDM in clinical genetic practice.
Objectives:	• To interview healthcare professionals about existing and past experiences of EDM including support and resources accessed. • To develop an initial design for an online resource based on the development of prototype material and informed by the medical literature. • To consult interviewees about the initial design for the online resource to gauge the level of interest in such a resource and to understand its function, value and any barriers to its implementation and use
Research questions:	• What are the experiences of different Clinical Genetics healthcare professionals in EDM? • What are the opinions of Clinical Genetics healthcare professionals on the development of a resource to support EDM in practice? • How might these experiences and opinions be used to shape the design of a resource to support EDM in practice?

Methodology & Methods

- Qualitative methodology:
  - Explore experiences, retain context, explore contradictions & interpret meaning
- Ethical approval:
  - IRAS reference 292500
  - 'Ethical preparedness in Genomic Medicine (EPPiGEN)' project – CELS group.
- Development of preliminary material:
  - Development of prototype case and design for resource
  - Presented at virtual Genethics Forum meeting on 26th November 2021
  - Expressions of interest requested to take part in interviews
    - Aimed for 8-10 participants, purposive sampling
    - Attended at least 1 Genethics meeting and working in a healthcare setting

Case

Main ethical issues and possible options

Clinical details relevant to the case

Review of the ethical issues

- Similar cases in literature
- Ethical arguments in published literature
- Evidence from empirical research studies
- Suggestions from relevant Genethics forum discussions

Professional guidelines

Relevant legal guidance

Suggested approach to adopt in similar cases

Interview strategy, data collection and analysis

Interviews:

- Email interview
- Follow up in-depth, semi-structured interview
  - Virtual, up to 60 mins

Thematic Analysis

ORTHOGRAPHIC TRANSCRIPTION & FAMILIARISATION

GENERATE INITIAL CODES

SEARCH FOR THEMES

REVIEW THEMES

DEFINE & NAME THEMES

REPORT

Results - Demographics

- 18 expressions of interest
- 10 email interviews
- 9 completed 'cases'(email & follow up interviews)

Variable		**n**	
Country of Practice	United Kingdom	9	
	Italy	1	
Attended Genethics meeting	Yes	10	
	No	0	
			Mean years in current role
Current role	Nurse Practitioner	1	1.5
	Genetic Counsellor	3	13
	SpR in Clinical Genetics	3	2.8
	Consultant in Clinical Genetics	1	33
	Clinical Scientist	1	32
	Bioethicist	1	5
		Years	
Years working in genetics/genomics	Total of all participants	155	
	Mean	15.5	
	Range	1.5 to 36	
Years working in healthcare	Total of all participants	174.5	
	Mean	19	
	Range	7 to 43	

Experiences of ethical decision-making & what is needed to support this

Theme 1: Culture & Community in supporting the challenges of EDM

Shared culture

- Desire to practice good medicine
- Deep engagement with ethical issues
- Despite practical and emotional issues that make this difficult

PRACTICAL ISSUES	EMOTIONAL ISSUES
Increased demand for testing • Resource allocation • Addressing inequities	Personally distressing • Conflicts with own values • ‘Fraught’
Heavy workloads	Isolating
Time constraints, time–limited decisions	Question own judgement
Changing ethical issues	Sit with uncertainty
Changing societal values	
Evolving roles and responsibilities	

‘You get an ethical case and you don’t have time to think about the ethics of it because it has to be reported you know... within 28 days... 42 days or whatever... so you don’t really have time to... to wrangle with the ethics too much...’ [HCP3]

‘There are some people who practised over these time periods where everything’s changed... so in the time period where... testing wasn’t possible to where testing is possible... to where prenatal diagnosis was not done for that and now it is’ [HCP6]

‘It [a group supervision session] was an opportunity to share difficult cases effectively... but very much from the perspective of a... of... feelings emotions... and necessarily that would often involve difficult ethical discussions that had come up […] it acknowledged a non-technical but very challenging aspect of our work... it acknowledged that work as difficult? So the fact that that time had been set aside seems to validate the importance of that part of the role’ [HCP1]

Discussion is key

- Consider alternate courses of action
- Solutions emerge through discussion
- Share past experiences
- Validate decision-making
- Source of support
- Community

‘Experienced genetic counsellors would chip in and say “Well I’ve seen this before… this is how we managed it” […] or just to provide some general sympathetic comments.’ [HCP1, when describing a group supervision session]

‘Conversations often follow like an iterative process... where things are clarified by degrees...? And... solutions they kind of emerge […] I think that is the kind of solution that gives people the most satisfaction... if you see what I mean... where there is an apparent community effort […] one of the most valuable components of meeting with other people.’ [NHCP1]

‘One of the real beauty of the Genethics meetings is it’s a really safe environment to kind of put ideas out there and say things and see what everyone else feeds back’ [HCP4]

Not all discussion is equal

Discussion less effective when:

- Small number of dominant voices
- Hierarchy within the group
- Unable to question an approach
- Reluctance to disagree with colleagues
- Lack of ethics 'expertise'
- Lack of time to address issues

Genethics Forum - effective

- 'Safe space'
- Absence of hierarchy

> *'It's the ethics but it's also the direct interaction... the community reflecting together... the sharing of questions and also the support...' [NHCP1]*

Use of existing clinical ethics support services

Setting	Clinical Ethics Support
Individual	Guideline or literature review Drawing on past training or other roles in education or policy-making
Small group	Discussions with colleagues or supervisors Group supervision sessions
Large group (non-specialist)	Local departmental meetings
Large group or specialist	Expert opinion Hospital ethics committee National meeting (e.g., Genethics)

Theme 2: Opportunities to learn and reflect

Lack of ethics resources outside of Genethics meetings

Contrast with larger specialties, or ‘scientific’ material

Existing ethics resources:

- Inaccessible
- Lacked confidence to access social science literature
- Needing specialist expertise in ethics

> *‘I just haven’t found particularly user-friendly resources and the hardcore ethics is helpful for some people but if you don’t have a formal ethics training background… and… and… you know… there’s a difference between applied… applying that and understanding the principles…’ [HCP4]*

Need for outcomes?

Ethics as nuanced & contextual

Requiring reflection on options

Case-by-case approach

Need for outcomes from Genethics meetings

Genethics as a platform for guideline development

How can we interpret this?

- Consistency, equity
- Workload and time constraints
- On the ground experience influencing wider debate?

But might encourage reliance on regulatory frameworks /defensive medicine

How could an online resource support ethical decision-making?

CULTURE & COMMUNITY

LEARNING & REFLECTION

Online ethics resource

(Generally) strong support for online resource

- Capture cases, discussion and experience of Genethics forum
- **Support ethical decision-making in practice**

Additional roles:

  - Teaching
  - Research tool

Complementary to Genethics meetings

> *‘To support decision-making… supporting ethical decision-making which involves clarifying the issue at hand... […] identifying the stakeholders... perhaps testing two or three different approaches... reflecting on the approaches and then you move on to actually enacting them…’ [NHCP1]*

’I can foresee that this resource might be used by individuals in their office researching a particular case and… and taken no further… it might.. it might confirm somebody’s already strong ideas about a particular decision that they were going to make and it might just provide them with reassurance that that is the right path and what others might do…’ [HCP1]

‘This resource might be able to empower teams to be able to say... “Okay... well... you know... we could have a discussion locally but perhaps if you look at a resource that Genethics have created that… that can be used locally to help guide our discussion a little bit to make sure that we’re not missing any of the key kind of pros or cons of different approaches...’ [HCP4].

How could an online ethics resource support culture and community?

Culture:
- Pique interest - material that is thought-provoking & engaging
- User-friendly, easy to navigate

Community:
- Real-time access
- Interactive
- Range of opinions (including ethicists, lawyers, social scientists, patients & lay public)
    - Genethics discussions
    - Interviews
    - Editorials

Recreate belonging & connection:
- Links to Genethics Forum
- Option to contact case contributor
- Ability to contribute material

Comment function???

- Popular suggestion – recreate discussion element
- Concern – potential for spam or abuse, privacy breaches & need for moderation

‘It [commenting] gives people the opportunity to feel that they are investing in the content as well by you know... by commenting they’re becoming a part of the resource?’ [HCP4].

‘I don’t know whether this community dimension... the dialogic dimension... would perhaps be lost... because the way this confirmation is reached I think is very valuable... I think this emergent quality... is something that I would... I can’t see how you might... replicate that...’ [NHCP1]

How could an online ethics resource support learning and reflection?

Ethics ‘knowledge base’

Access to Genethics cases & discussions

Reference to guidelines & literature

Concise yet potential for detail

Layered approach

Encourage reflection by emphasising process

Non-didactic approach

- Workflows
- Changing scenarios

Not a ‘just-in-time’ resource

‘You don’t come to the Genethics to get a right or a wrong answer... the case still has to be worked through by... by the people involved... so I wonder if that needs to be part of the preamble that it’s not about answers... it’s about process’ [HCP9]

Not do the work of ethics for others

‘If the resource is something that people can turn to five minutes before seeing a case where the referral letter suggests there may be a problem, then it will be used as a substitute for real thought and engagement on the part of the clinician (medic or GC [genetic counsellor]). If it is an educational tool, then it will be much less damaging but might still help people save time and thereby avoid having to think so hard for themselves.’ [HCP10, email interview]

Theme 3: Everyone needs ethics and ethics needs everyone

- All may benefit from the resource
- **Clinical Genetics**
- Mainstream Clinicians
  - Especially Oncology, Fetal Medicine, Paediatrics

- Different needs:
  - Lack of familiarity with issues
  - Structure (eg condition-specific)
  - Concise?

Could a resource support patients too?

Support patient decision-making

- Maximise fairness & utility
- Used with HCPs – especially in case of disagreement

Concerns about patient access

- Provoke anxiety
- Lose safe space
- Issues might be sensationalised

Separate interface or restricted access

‘It might be a good way of allowing them [patients] to… to try and understand why you’ve… you know… you’re withholding… you know their relative’s information or why you’re suggesting that testing their child’s not a good idea… or…you know it might be quite a good way to provide them with information without… you know… on their own terms and in their own time’ [HCP2]

‘In a way some of it might be a little bit terrifying for patients to access like issues around non-paternity for example that non-paternity might not be disclosed […] it’s not about being paternalistic but it’s helping patients to avoid worry or... you know... things that they… they haven’t got the training to help them to understand... and I guess my only worry with patients accessing it is... (pause) do we open up a bit of a can of worms as to things that they… that might… cause further difficulties rather than help them...’ [HCP4]

‘I wonder if a discussion could be sensationalised or used... in a way that obscures the nuance and the care that our discussions encompass... so if something is widely open... does that make a difference to how a conversation might be had or how the outcome of a specific case is discussed elsewhere? [HCP6]

Ethics needs everyone

Ethics should be informed by society

‘Ethics is for the people’ [HCP3].

Accessing patient opinion challenging

- Patients might not know cases discussed
- Don’t routinely attend Genethics meetings
- Patient interest groups
  - Don’t represent all patients
  - Don’t represent society

‘I just wonder if there’s a missing element where we don’t… can’t or won’t or don’t speak about certain points of view... and I would hope that this one [resource]… this would be really open... to look at why certain families don’t partake or why they will do things that are maybe not in their own best interest...’ [HCP6]

Use of patient cases

- Essential to demonstrate ethical issues
- Real cases would demonstrate context and nuance
- Detailed or unusual cases might breach privacy
- Some suggested patient consent necessary
  - How to approach patient for consent if don’t know case discussed?
  - Who to approach for consent?
  - Issues where consent isn’t feasible – under-represented
- Balance to be struck
  - Changing details or using composite cases should be sufficient

‘My understanding is that when we’ve discussed patients at Genethics a bit like where we discuss patients at in-house meetings for example we’re fundamentally furthering the patient’s care […] I think patients would consider an online resource to be different… […] I think it would probably be best to get explicit consent from them [HCP1]

‘This is really tricky because in our field many conditions are very very rare… you probably wouldn’t be able to use those names […] this is where the balance is so if you have an entirely open resource which is entirely anonymised the worry is do you then make the information so bland that it really doesn’t speak to anyone’s real ethical experiences anymore [HCP1]

‘I mean where you can illustrate the point well enough without the full case details then I'd say composite and or tweaking details to change things is the easier way to go… […] tweak details and maybe merge one or two cases to… to get around that [consent] I think…’ [HCP10]

Supporting situated ethical decision-making in genetic medicine

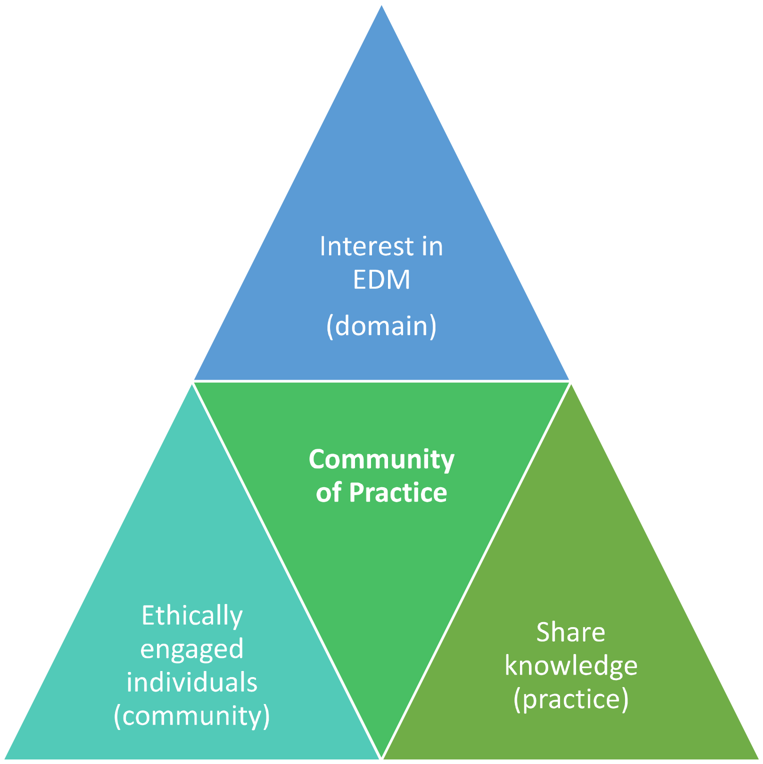
The Genethics Forum supports ethical decision-making

Tacit knowledge supported by observation, imitation, conversations, stories & metaphors

- Enriched with ethically engaged individuals
- Safe space
- Dedicated time
- Absence of hierarchy
- Opportunity to reflect and learn
- Emergent quality of discussions
- Support each other

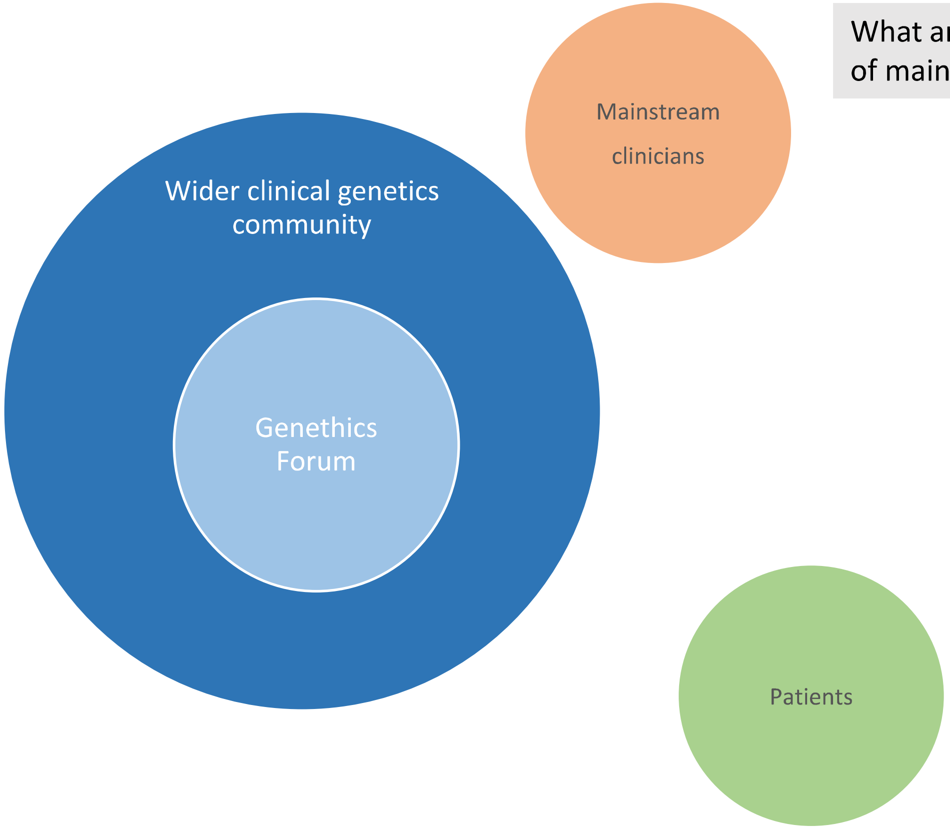
Genethics is a Community of Practice

"groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise by interacting on an ongoing basis“



Noar et al. 2023

Communities of practice in Genetic Medicine



Wider clinical genetics community

Genethics Forum

Mainstream clinicians

Patients

What are the ethical decision-making experiences of mainstream clinicians?

How might patients access, draw on and benefit from ethics support?

Virtual communities of practice in Medicine

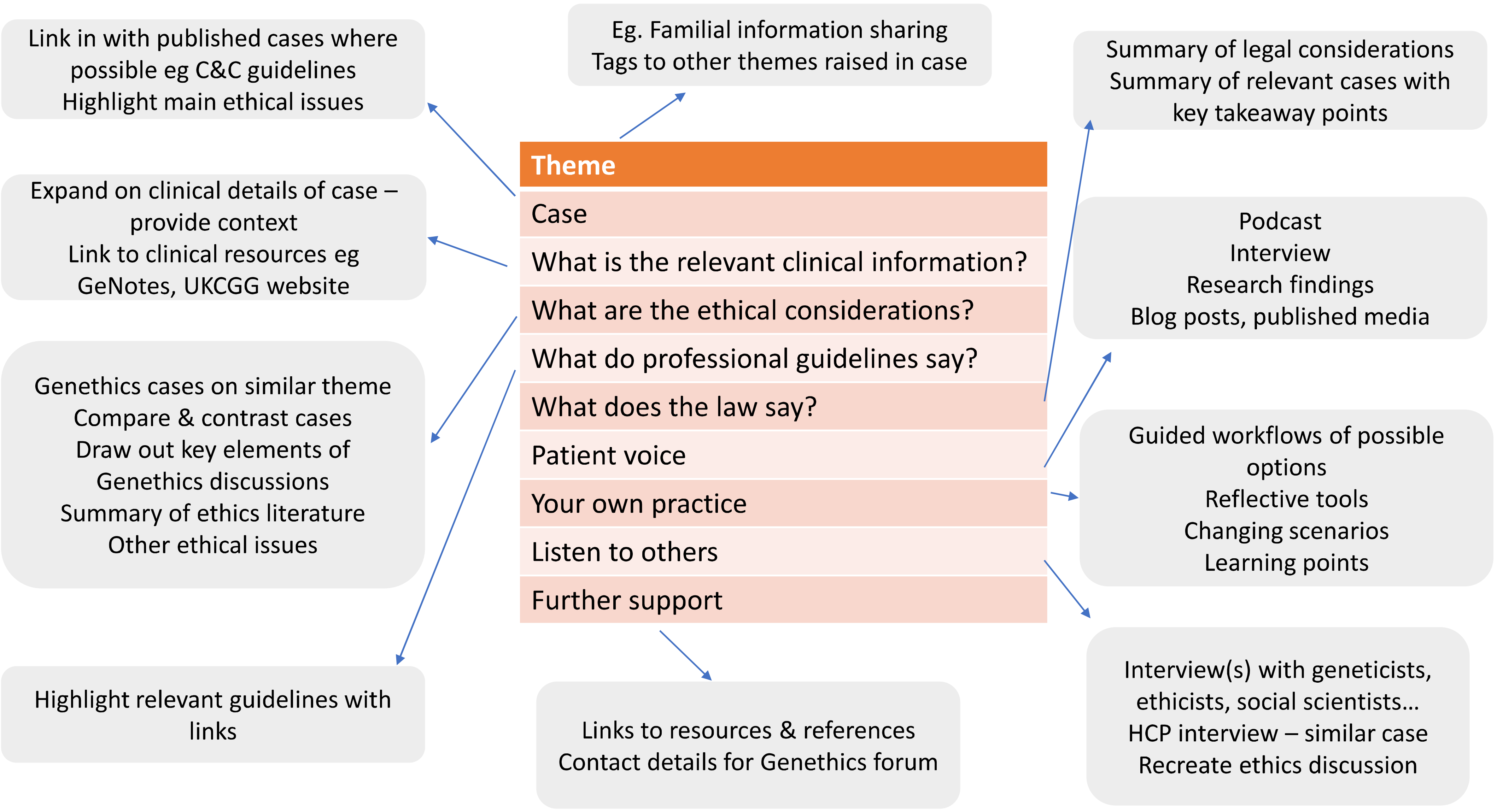
ONLINE PLATFORMS

TO DISSEMINATE KNOWLEDGE

ENCOURAGE INTER-PROFESSIONAL COMMUNICATION

Creating a virtual Genethics Community of Practice

Culture	Thought provoking, interactive	• Questions • Flow chart • Changing scenarios • ‘Games’
	Engaging	• Limit text • Videos
Community	Range of perspectives	• Clinicians, ethicists, social scientists, patients, general public • Genethics discussions • Interviews • Editorial pieces
	Belonging and connection	• Comment/chat function??? • ‘Contact the clinician’ • Links with Genethics forum • Ability to contribute material
Learning & Reflection	Access to a knowledge base Real time access	• Cases • Genethics forum discussions • Literature and guidelines
	User-friendly/navigation	• Consistent layout • Organised into themes • Use of tags
	Concise yet detailed	• Layered approach
	Encourage reflection	• Non-didactic approach • Not providing answers



Theme

- Case
- What is the relevant clinical information?
- What are the ethical considerations?
- What do professional guidelines say?
- What does the law say?
- Patient voice
- Your own practice
- Listen to others
- Further support

Eg. Familial information sharing
Tags to other themes raised in case

Link in with published cases where possible eg C&C guidelines
Highlight main ethical issues

Expand on clinical details of case – provide context
Link to clinical resources eg GeNotes, UKCGG website

Genethics cases on similar theme
Compare & contrast cases
Draw out key elements of Genethics discussions
Summary of ethics literature
Other ethical issues

Highlight relevant guidelines with links

Summary of legal considerations
Summary of relevant cases with key takeaway points

Podcast
Interview
Research findings
Blog posts, published media

Guided workflows of possible options
Reflective tools
Changing scenarios
Learning points

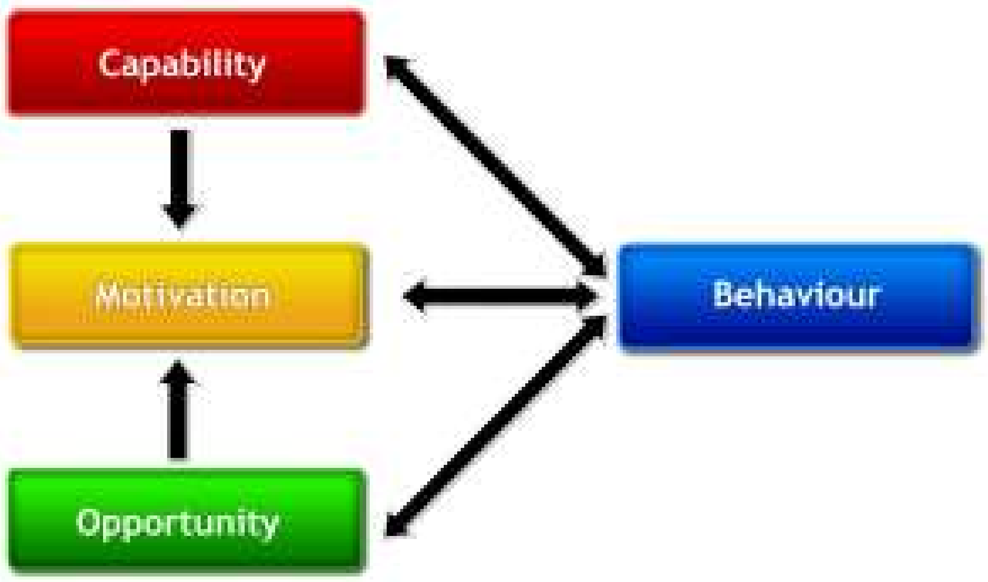
Interview(s) with geneticists, ethicists, social scientists…
HCP interview – similar case
Recreate ethics discussion

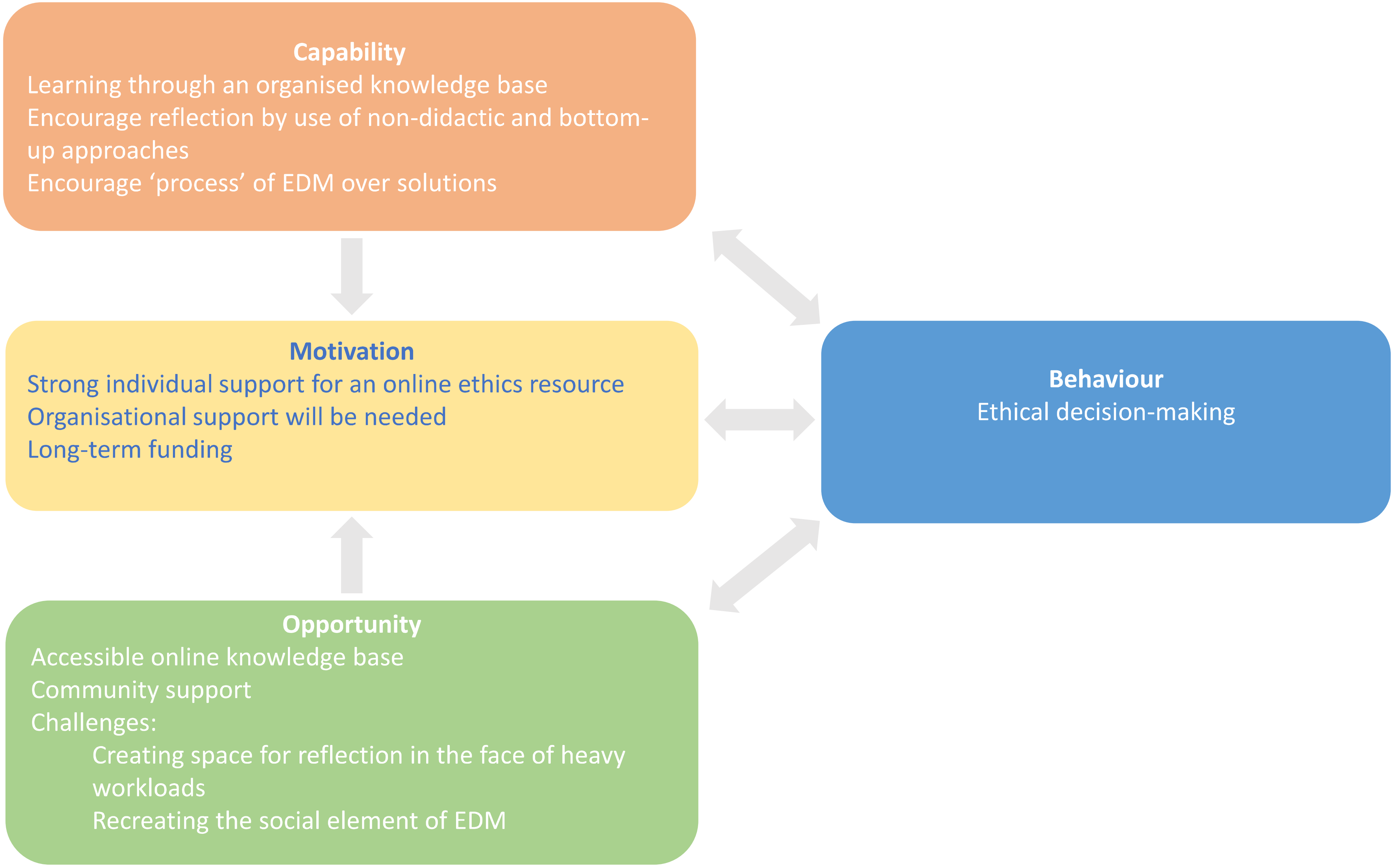
Links to resources & references
Contact details for Genethics forum

How could an online ethics resource foster ethical preparedness?

Anticipate, reflect on and respond to ethical challenges arising in everyday practice

COM-B Behaviour change model (Michie et al. 2012)





Capability
Learning through an organised knowledge base
Encourage reflection by use of non-didactic and bottom-up approaches
Encourage ‘process’ of EDM over solutions

Motivation
Strong individual support for an online ethics resource
Organisational support will be needed
Long-term funding

Opportunity
Accessible online knowledge base
Community support
Challenges:
  Creating space for reflection in the face of heavy workloads
  Recreating the social element of EDM

Behaviour
Ethical decision-making

Limitations

Reflexivity

- ‘Inside’ position (Genetics SpR)
- Personal ideas & ambitions

Practical challenges:

- Internet connectivity problems, fire alarm
- Gap between data collection & analysis

Transferability of data

- Genethics forum attendees - represents views of ethically engaged individuals
- Several participants inexperienced
- 1 Clinical Scientist, 1 Consultant
- Mainstream clinicians & patients not interviewed

What next for the online resource?

Resource to continue as a Genethics Forum co-design project

Iterative user feedback

Contribution of material

Continue as a research project to explore ethical preparedness

First case in development

Working with CanGene CanVar WP6 (Kate Sahan)

Potential collaboration with Genomics Education Programme

- GTAC
- ?MOOC

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Questions & comments?

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