NUFFIELD COUNCIL≌ BIOETHICS

SHARING BEST PRACTICE IN ETHICS & GENOMICS

Summary of case studies



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Key points

- There is a rich body of expertise and experience in the UK in considering the ethical issues raised in genomics healthcare and research. The Nuffield Council on Bioethics set out to gather and share best practice in this area through a call for case studies. We received 30 case studies from a range of organisations, both in the public and private sectors, which described examples from clinical practice, research and policy.
- The case studies showed that the reasons that people are thinking about ethics are varied, but it is possible to identify common themes across the ethical issues that are encountered. These include the weighing of benefits and harms, gaining consent from participants and patients, understanding public values, addressing inequalities, and deciding what findings to return.
- There are also commonalities in the ways people are considering ethical issues, with many seeking input from experts, patients and the public, and consulting research evidence and professional guidance. Discussion and deliberation are also a regular feature. However, there are clearly differences in the resources and time that are available to think about ethics and engage with stakeholders.
- Thinking about ethics can have tangible impacts, for example on professional practice, organisational policies, and the skills and knowledge of professionals.
- The challenges that have been encountered are many and wide ranging. Most could not find off-the-shelf answers to the ethical questions they faced, and some have come up against misperceptions about what ethics can offer and difficulties in engaging a wide range of views.
- There is a willingness to share learning and experiences, and many find it helpful to be able to discuss with others the challenges and ethical issues they encounter.

Introduction

Between July and September 2022, the Nuffield Council on Bioethics called for case studies that illustrate how people in the UK are considering the ethical issues raised by genomics healthcare and research initiatives. We wanted to hear about the range of approaches being taken to identify common themes and examples of best practice.

The call was part of a Nuffield Council project that is supporting the UK Government to reach its commitment, in the <u>Genome UK strategy</u>, to establish a gold standard UK model for how to apply strong and consistent ethical standards in genomic medicine and research. The project is being carried out in partnership with representatives of national genomics initiatives in the four countries of the UK (the Office for Life Sciences, Scottish Government, Genomics Partnership Wales, and Public Health Agency, Northern Ireland).

Method

The project partners promoted the call for case studies across their networks and contacts and through social media. We asked for case studies that showed the kinds of ethical issues raised by genomics initiatives, how people had gone about considering these issues, and what challenges had been experienced. Case studies were sought from the past 10 years (2012-2022) and could include those undertaken by healthcare services, governments, academia, and the charity and private sectors.

Genomics initiatives were defined as those that fell in or across the three pillars of the Genome UK strategy – diagnosis and personalised medicine, prevention, and research. We were primarily interested in examples from the UK, but international case studies were welcomed as comparators.

Thirty case studies were received (see Annex for list). The content was analysed and summarised by staff at the Nuffield Council, then reviewed by members of the Nuffield Council and the project partners.

This report summarises the types of case studies received, the ethical issues that were encountered, the reasons for thinking about ethics, how people went about thinking about ethics, the challenges they faced, and the outputs and impact. The findings are not quantified given the small sample size. The aim of this summary is to show the range and breadth of the issues and approaches described in the case studies.

Types of organisations

The types of organisations that were featured in the case studies included:

- NHS clinical centre
- Academic research centre
- Higher education provider
- Not for profit private company
- For profit private company
- International organisation

- Government department or body
- NGO / independent body
- Professional body
- Discussion forum
- Biomedical database

Types of case study

All the case studies were related to initiatives that involved genomic testing or screening, or research on the link between genes and health. The types of case study included:

• Design of clinical, scientific or technical research

- Design of a clinical service or screening programme
- Design of a hybrid research-clinical programme
- Development of organisational policy
- Development of profession-wide or international guidance
- Policy-focused inquiry or review
- Ethics or social science research
- Public or patient engagement initiative
- Professional education or training
- Discussion forum
- Ethics advisory group
- Individual patient case study

Some case studies fell into more than one category. Most described activities that had taken place in the UK, apart from three which had distinct international elements.

Why did people think about ethics?

A desire to consider public and patient values, perspectives and needs was a common reason for thinking about ethics. People wanted to align genomics initiatives with public values and gain public trust, and incorporate public and patient views in the design of services and policies.

Other reasons for thinking about ethics differed depending on the kind of initiative.

Reasons relating to the design and conduct of a research study, clinical service or screening programme included:

- Meet ethical and regulatory standards
- Anticipate and mitigate harms
- Help navigate novel research design and methods, or a novel area of medicine
- Ensure safe interpretation of genomic data
- Gain informed consent from participants or patients
- Improve patient experiences
- Develop methods to anonymise genetic data
- Reduce the environmental impact of genomics

Reasons relating to organisational policy included:

- Establish appropriate governance processes
- Inform the prioritisation of research
- Support different parts of an organisation to speak with a single voice
- Position organisation as a thought leader in ethics

Reasons relating to profession-wide standards included:

- Inform professional guidance
- Educate or up-skill professionals
- Share good practice
- Embed ethics in genomic medicine
- Address disparities in how people experience and benefit from genomics

Case study: Guidance on consent and confidentiality in genomic medicine

The British Society for Genetics in Medicine led work to revise professional guidance on sharing confidential genomic information with members of a patient's family. Issues explored included inconsistencies in the interpretation of the law and potential harms to family members through delays in offering a diagnosis. A multidisciplinary working group was set up which considered clinical cases brought to the Genethics Forum (see below) and empirical research. The revised guidance set out the importance of discussing data use in pre-test discussions with patients and that, in some cases, knowledge of genetic variants should be treated as confidential to the family rather than the individual. The guidance has been adopted by the JCGM and the Genomic Medicine Service, although concerns remain about how obligations to keep patient data confidential can be reconciled with the familial nature of genetic disease.

Reasons relating to national or international policy included:

- Inform national policy
- Evaluate justification for emergency measures
- Harmonise international policies and tools
- Support international research collaboration
- Protect people against genetic discrimination

Other more general reasons for thinking about ethics included: ensuring ethics keeps pace with scientific advance, ensuring research benefits everyone in society, and increasing our understanding of the ethical issues raised by genomics.

What ethical issues were encountered?

Common themes

Several ethical issues arose in most or many of the case studies, regardless of the type of genomics initiative or target audience. These were:

- Broadly, weighing the potential **benefits and harms** of genomics initiatives.
- How to obtain **informed consent** for genetic testing from patients or participants, and how decisions should be made about genetic testing in children and people who are not able to give consent themselves.
- Resolving the tension between respecting **data privacy** and facilitating the use of data for research and diagnosis.
- Understanding and aligning genomics initiatives with **public values**, for example in response to changing societal perceptions of disability and impairment.
- Addressing **inequalities** in how people experience and benefit from genomics initiatives, and mitigating the potential for genetic discrimination.
- Deciding what **findings** should be returned to patients/participants and their families, how to do this and whose responsibility it is.

Ethical issues encountered in research case studies

In addition to these common themes, data protection was a strong theme in the research case studies, where consideration was given to whether and how genomic data can be anonymised, access to datasets, and concern about misuse of data. The establishment of robust data governance processes and the potential for a social contract for use of genomic data in research were raised.

Issues such as complying with research regulations and laws, recruiting a large cohort in a non-coercive way, mitigating for the unintended consequences of research, and ensuring transparency of process were also raised in the research case studies.

Those involved in the research case studies thought about whether and how to involve vulnerable people, how to deal with any emotional harms of taking part, and how to recontact participants without causing them to withdraw from the programme or breach earlier promises. There were questions relating to the timing of the consent process, and handling the withdrawal of patients and their data from research.

Questions relating to the findings of research included understanding the risks and benefits of sharing findings with participants, how accurate genomics tests need to be, how clinically relevant findings should be managed and how participants should be supported with those (while being mindful of not placing burdens on the NHS), and the right not to know the findings of genomic tests.

On a societal level, importance was placed on gaining patient and public support for and trust in research. There was awareness of public concern about eugenics and profiteering, and societal perceptions of disability, although there was uncertainty about whether attitudes might be changing around these issues.

Other issues raised included how to address the lack of diversity in genomic datasets, inequalities in research on different diseases, digital exclusion, genetic discrimination, and the environmental impact of genomics databases and research.

Case study: Genomics England Newborn Genomes Programme

Genomics England is undertaking a research study to explore the benefits, challenges and practicalities of sequencing and analysing the genomes of newborn babies. The ethical issues span the limitations of consent in the context of genomic screening research, the rights and needs of the child and those of the wider family, the benefits and harms of sharing screening results in a pre-symptomatic context, and equitable access and the potential for discrimination. To consider these issues, an ethics lead and independent ethics working group are drawing on and deliberating existing and commissioned research, a public dialogue exercise, other engagement activities, and operational expertise to inform the design of the study and its evaluation. The team have faced challenges relating to the novel nature of the study and its regulatory approvals, tight timelines, and balancing ethical considerations with technical, operational and economic ones. To date, the ethics work has led to the development of a comprehensive consent model, changes in the language used to describe the study and a focus on participant benefit and harms, with engagement and communication sitting hand-in-glove with ethics.

Ethical issues encountered in clinical case studies

The ethical issues encountered in the clinical case studies commonly related to the delivery of genomic services to patients. These case studies were mindful of the need to show respect for patients and to make decisions in their best interests where necessary.

Issues relating to gaining consent from patients for genomic testing were commonly raised, particularly where the patient lacked capacity or when the test needed to happen very quickly. There were attempts to understand the factors affecting patient decision making around genomic testing.

On the theme of data protection, clinical case studies were concerned with the interpretation of UK data protection law and how to work with differing data privacy laws in other countries. There were questions over whether to contact an anonymous egg donor to request a DNA sample, and share confidential genetic information with family members of patients.

Other ethical issues relating to the sharing of findings included whether and how to return unexpected findings to patients, the psychological impact of non-actionable findings, and the impact of inequalities on the ability of patients to share relevant findings with relatives.

Clinical case studies also considered the benefits and harms of offering whole genome sequencing vs targeted testing, the ethics of not piloting a new test that could improve patient care, and considerations of when it is ethical to advocate for a new test in relation to the availability of treatments for that condition.

Wider societal issues were encountered in several clinical case studies. These included understanding public views on reproductive autonomy and choice, e.g. around preimplantation and prenatal diagnosis, and views on the fair use of public resources for genomics services. The potential for discrimination and stigmatization following genetic testing, for example in the context of insurance, and inequity of access to services was also considered.

Case study: Genetic testing for a child awaiting adoption

A decision about whether to conduct a genetic test for a child awaiting adoption highlighted that different services, such as social services and clinical genetics, can have different approaches to genetic testing of children. Drawing on professional guidance, the case was discussed with a range of health and care professionals and consensus was reached: genetic testing should be conducted, given the potential harm to the child's adoption success of delaying the test. Those involved in this case found discussions with clinical colleagues to be helpful, and suggest a more strategic approach to genetic testing for children within the care of the state should be considered.

Ethical issues encountered in screening case studies

The ethical issues encountered in screening case studies commonly related to balancing respect for individuals with improving population health.

At a policy level, issues arose in relation to the criteria for introducing predictive testing, how the requirement for actionable findings should be interpreted, and the timing of screening in a person's life to optimise health benefits and informed choice.

Difficult questions about the societal acceptability of prenatal screening had been considered, and how this relates to prejudice, bias and discrimination for people with genetic conditions.

Issues encountered in relation to childhood screening included the meaning 'actionable in childhood' and whether it is acceptable to have a delay between the screening test and the commencement of treatment. Balancing the needs and interests of children being offered

genetic screening, along with those of the wider family who might also benefit, had challenged long-established principles of screening.

Other ethical issues in the screening case studies included the implications of sharing results with people at a pre-symptomatic stage, and public and patient views on the balance between certainty of test results and the number of cases that might be missed.

Case study: The use of next generation sequencing in newborn screening for cystic fibrosis (CF)

Following a feasibility study, two approaches for incorporating next generation genomic sequencing in CF newborn screening emerged. One would favour test sensitivity, meaning fewer cases of CF would be missed but could result in uncertain results for some families. The other would prioritise test specificity, accepting that some CF cases may be missed. The research team assessed stakeholder views on these options through a commissioned public dialogue. The participants initially expressed a clear preference to maximise sensitivity and avoid missing CF cases, but after time to reflect and consider the implications of their choice, a number changed their views to tolerate some missed cases if this resulted in greater certainty of outcome. This became the majority view. The team accept that the experts who presented during the dialogue may have influenced this outcome (described in full in an <u>open access journal</u>). Further engagement to explore the views of families with lived experience and health care professionals is ongoing.

Ethical issues encountered in hybrid case studies

Some case studies described initiatives that cut across research, clinical service and, in some cases, technical innovation. These case studies encountered particular challenges relating to the coming together of norms and practices of different sectors, and the navigation of different cultures, and regulatory mechanisms.

How did people go about considering ethical issues?

Types of input

The types of input that were sought to help people think about ethical issues included:

- Multi-disciplinary expertise e.g. clinical, science, ethics, law, psychology, sociology, policy, insurance
- Patient views and experience directly from patients and indirectly through patient groups
- Public views and experience
- Research evidence
- Professional guidance and organisational policy
- International comparators

Methods

The methods people used to gain this input were wide ranging and included:

- Expert advisory panels and working groups, discussion fora, clinical meetings, conference discussions, and other ways to facilitate multidisciplinary deliberation.
- Patient advisory groups and co-production of services, policies & materials.
- Public engagement exercises, standing committees of members of the public, public events, and online engagement platforms.

- Empirical research such as interviews and focus groups.
- Reviews of national and international literature, guidance and policy.
- Open consultations and surveys.
- Employment of staff to lead on ethics, appointment of ethics experts to organisational committees, and initiation of a separate ethics workstream.
- Research ethics committee review and peer review.
- Professional education and training.

Many case studies highlight that these methods are not one-offs and that there is an ongoing process of ethical analysis and monitoring of standards in their organisation.

Case study: Genomics Partnership Wales' Public and Patient Sounding Board

The Patient and Public Sounding Board was established to ensure that meaningful coproduction underpin all aspects of strategy delivery to ultimately improve patient experiences and clinical service delivery across Genomics Partnership Wales. The inclusion of patient and public perspectives on ethical implications is deemed critical, and practitioners are encouraged to consult with the Sounding Board when developing services, research proposals, engagement activities or healthcare policies. For example, the Sounding Board was consulted on the preferred approach to reporting incidental findings from genomic testing to the patient and their family. Their discussions directly influenced an incidental findings policy for the genomics service in Wales. To ensure a wide representation of experiences, robust recruitment processes are used which value demographic diversity, source materials are provided that use easily understandable language, difference of opinion is respected, and each session has a consultation lead who maintains an 'active listening' approach throughout.

Types of outputs

The findings and outcomes of ethical consideration resulted in outputs including:

- Journal articles, publications, reports and presentations
- Professional guidance and toolkits
- Patient/participant information, support, tools and consent forms
- Ethics and governance frameworks and principles
- Organisational strategies
- Advice on the design of research or services
- Scientific tools and open-source code
- Training courses

What was the impact of thinking about ethics?

Thinking about the ethical issues raised by genomics had a range of different impacts.

Changes to policy and practice

Some case studies described how thinking about ethics had directly influenced or initiated the development of professional guidance, or led to changes in professional practice. Many initiatives had contributed to the design, conduct and evaluation of research. The contributions of ethics included highlighting sensitivities and potential unintended consequences, and managing differences in perception and approach.

Some initiatives had influenced regulation and led to improved standards, e.g. in the genetic testing sector. Others had informed the way national screening decisions are made and

influenced the design of screening proposals. A few reported that their findings and recommendations had not been influential.

Organisational change

Thinking about ethics had informed organisational governance structures and embedded patient and public voices across organisations. It had led to improved communication with diverse audiences and more generally resulted in an increased focus on patient and participant benefit. Some felt that their work had reduced the burden on organisations to consider ethics.

Case study: Novartis principles for genetic testing

Government policies for screening, genetic testing and testing for genetically driven risk factors may have significant influence on patient access. Therefore, Novartis engages in discussions with healthcare policy makers to help ensure medicines are accessible to as many patients as possible. To enable a better internal understanding of the different elements of these discussions, including the ethical aspects, a set of principles was developed. While drafting the principles, a range of ethical issues were identified through internal discussions and double-blind interviews with external experts across geographies and stakeholder groups. The principles, which are used by colleagues across Novartis, provide consensus across therapy areas on identified issues and ensure a one voice approach for external discussions. The process helped colleagues become aware of potential sensitivities and unintended consequences of genetic testing and screening, and highlighted cultural differences in the use of the term 'ethics'. The current principles are viewed as a basis for further discussion and may evolve in line with increasing public awareness and scientific progress in the field.

Building skills and knowledge

Many case studies described building ethics skills and knowledge in genomics and other professionals. Some had directly informed or delivered professional education or training. Others felt their work had furthered 'ethical literacy' among professionals generally and empowered them to raise ethical issues and think about ethics in context. Some initiatives had helped professionals interpret guidance and law.

Stimulating discussion and collaboration

Several case studies reported having an impact on the stimulation of debate, reflection and interdisciplinary exchange. Some had led to the formation of new or strengthened partnerships e.g. between a research programme and the NHS, or the creation of new professional networks both in the UK and in other countries.

Case study: The Genethics Forum

The UK's Genethics Forum provides an opportunity for professionals, trainees and researchers in clinical genetics to discuss the practical ethical issues faced in their work. Ethicists, lawyers and patient group representatives also participate in the meetings. Discussions focus on the often complex and intertwined ethical issues arising from cases presented. There can be barriers to people attending (e.g. perceptions they should already know what to do, or will be told what to do). However, participants value having a confidential space to discuss ethical issues, hearing a range of perspectives, and feel more confident about raising ethical issues. The lack of long-term funding has been a challenge.

Contributing to the practice of ethics

Furthering knowledge and understanding of ethical issues in genomics was an outcome of some case studies, as well as demonstrating the value of ethical thinking. In some cases, accessibility to ethics tools and discussion had been increased.

Challenges

The challenges that had been experienced across the case studies were many and wide ranging.

Reluctance and misperceptions

The kinds of challenges that were most commonly cited in the case studies related to a lack of awareness of what ethics can offer, and a reluctance on the part of others to think about ethics.

Some felt that ethics was less valued that other aspects of genomics and that there was a perception that ethics is inherently critical and obstructive. People experienced difficulties engaging decision makers and convincing them there were unresolved ethical issues to be addressed.

People came across the perception that ethics is only concerned with regulation and law, and that ethics will provide a yes or no answer. A further problem was that terms around ethics, such as data sharing, are not used consistently, particularly across different cultures.

In trying to engage people in ethical thinking, there were reports of people thinking ethics was not their job or that they should already know the answer, making them unwilling to engage.

Communication and engagement

Most case studies involved concerted engagement with stakeholders, but this had created challenges relating to managing conflicting views, handling vested interests and talking about sensitive topics.

Ensuring diversity on panels and groups could be difficult to achieve, as was reaching beyond the loudest voices. Facilitating exchange of ideas between practitioners and 'thinkers' could be challenging.

Clear communication of the aims of research had been difficult to achieve for some. Others were unclear about how much engagement was enough, and at what stage engagement should happen.

Some cited having to use unwieldy consent processes and challenges around involving people who have communication issues.

Practical challenges

The practical challenges that people encountered included a lack of funding for ethicsfocused work, short time scales, and delays in obtaining the appropriate paperwork.

Others had found the engagement elements of their initiative very resource intensive and time consuming. Covid-19 lockdowns had added further challenges to engagement activities.

For some, there was a lack of co-ordination between key bodies and organisations that interact with genetic services, and different decisions made elsewhere in clinical pathways had to be managed.

Developing findings and conclusions

A key challenge for some was that they were dealing with a novel research or clinical programme with no precedents on which to draw.

Reaching consensus in contested or contentious areas had been problematic or impossible for some. In some cases, the contribution of multiple voices had led to complex and seemingly contradictory conclusions. Some were left with unresolved issues, such as how to collaborate with countries with poor data protection.

Balancing ethical considerations with technical, economic and operational factors was an added complication, and as was creating outputs that could be applied in multiple contexts or countries.

Sharing good practice

Some case studies described what had worked well, and the ways in which they had overcome challenges. Many had built their knowledge through learning from others and were keen to share their experiences.

Many had found it helpful to be able to discuss ethical issues with others in the early stages of an initiative, and on an ongoing basis. Examples of places where discussions took place included the Genethics Forum (see case study above) and multidisciplinary conferences and meetings. A new forum for the discussion of social and ethical research in genomics (the SERG network) has recently been established.

When engaging with different people, it was felt important to respect diversity of opinion and be transparent about differing views in any reports or other outputs. The interests of panel members should be publicly declared.

Members of the public need time to consider ethical issues and arrive at a view, and evidence on patient and public views should be sought regularly, given these can evolve over time. Those contributing their views should be provided with support to enable them to take part and to manage any emotional aspects.

To reach consensus in their findings, some had found it helpful to have multiple rounds of revisions and discussions. Some findings were not viewed as the last word and would be evaluated as the conversation continued.

Annex. Case studies submitted

Name(s)	Organisation	Name of initiative
Alison Hall	British Society for Genetics in Medicine (BSGM)	Analysis of the ethical and legal framework relating to consent and confidentiality in the use of genetic and genomic information in the clinic
Angus Clarke	Cardiff University	Ethics teaching in Cardiff University MSc Course in Genetic and Genomic Counselling
Angus Clarke	Cardiff University, University of Southampton, University Hospitals Plymouth NHS Trust, Aalborg University, University of Exeter, Cardiff and Vale University Health Board, Royal Devon and Exeter Hospital, University Hospitals Bristol NHS FT	Framing the trajectories of decision- making in the context of predictive and prenatal genetic and genomic tests
Anneke Lucassen	UK Biobank	UK Biobank Ethics Advisory Committee
Anneke Lucassen & Bobbie Farsides	Brighton and Sussex Medical School and Centre for Clinical Ethics and Law, University of Southampton	Ethical Preparedness and developments in genomic healthcare
Arzoo Ahmed & Natalie Banner	Genomics England	Newborn Genomes Programme
Catherine Joynson	Nuffield Council on Bioethics	The ethics of non-invasive prenatal testing
Catherine Joynson	UK National Screening Committee	Ethical analysis of child-family cascade screening for familial hypercholesterolemia (FH)
Colin Mitchell	PHG Foundation	Regulation and use of confidential patient data for genomic and medical research during and post COVID-19
Colin Mitchell	PHG Foundation	The ethical and legal framework for a Genomics England and Sano Genetics participant engagement platform
Conor Griffin and Sasha Brown	Google DeepMind	Google DeepMind's approach to pioneering responsibly with AlphaFold
Elaine Lowey	IQVA	Genomic Anonymization Technology
Felicity Boardman Corinna Clark	University of Warwick	Imagining Futures: The Social and Ethical Implications of Genetic Screenings' and SERG network

Fiona Maleady-Crowe and Louisa Elias Evans	Our Future Health	Our Future Health
Gabby Samuel	King's College London and Oxford University	Wellcome Fellowship on adverse environmental and health impacts of genomics research
Helen Firth	Wellcome Sanger Institute & EMBL-EBI	DECIPHER
Helen Firth	Wellcome Sanger Institute and NHS Regional Genetics Services	The Deciphering Developmental Disorders study
Jim Bonham & Lauren Cooper	Public Health England	The potential use of next generation genomic sequencing as part of whole population newborn screening for cystic fibrosis
Lisa Ballard	Data-Gen-Ethics, an interdisciplinary research group at the University of Southampton	Exploring ways to make the sharing of genetic test results with relatives more likely
Maili Raven-Adams	GA4GH	Regulatory and Ethics Work Stream
Mareike Ostertag	Novartis	Novartis principles for genetic testing and testing for genetically driven risk factors
Michaela John	Genomics Partnership Wales	Involving patient and public voices in shaping genomics delivery in Wales
Rachel Thompson	CELS research group (Clinical Ethics Law and Society) at the University of Oxford and University of Southampton	CELS research group (Clinical Ethics Law and Society) at the University of Oxford and University of Southampton
Roya Ziaie	Department of Health and Social Care and the Association of British Insurers	Code on genetic testing and insurance
Sasha Henriques	Guy's and St Thomas's NHS Trust	Genetic testing in a breast cancer patient with a learning disability
Sasha Henriques	Guy's and St Thomas's NHS Trust	Decisions about genetic testing in a child awaiting adoption
Sasha Henriques	Guy's and St Thomas's NHS trust	Addressing disparities in genetic outcomes for diverse populations
Tara Clancy	Genethics Forum	Genethics Forum
Vivienne Parry	Genomics England	Establishing a Participant Panel for the 100,000 Genomes Project
Anonymous	Anonymous	Anonymous

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