



Correction to: Co-designing models for the communication of genomic results for rare diseases: a comparative study in the Czech Republic and the United Kingdom

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The original version of this article unfortunately contains mistakes introduced during the publishing process.

Tables 2, 3, 4 and 5 should be presented as below.

The original article can be found online at <https://doi.org/10.1007/s12687-022-00589-w>.

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Table 2 Themes from interviews with health professionals and discussion at the events

Czech site	UK site
Post-test care: need to follow up with families after results have been shared, and recommendations for improvements in this area	
Telehealth: improve accessibility to facilitate communication with families, including via email and/or digital consultation	
Multidisciplinary approach: improve collaboration with non-genetic specialties as well as with allied health care professions (e.g. integrated service models).	
Education: about genomics in general and rare disease in particular, particularly among non-genetic specialties and in collaboration with patient organisations.	
Counselling skills: psychosocial support on challenging aspects of the family journey (e.g. expectation management, valuing negative results, managing feelings of guilt)	
Lab reports: accessibility of language and content of the reports for families and non-genetic professionals.	
Family-facing educational and information materials (e.g. improvements to service website)	Resources (e.g. workforce shortages, commissioning)
Service environment (e.g. wheelchair access, a suitable waiting room, a feeding and changing room for babies and toddlers)	IT and datasharing (e.g. patient database)

Table 3 Touch points from family interviews

Czech site	UK site
Personal utility: benefits families identified, including but not limited to the clinical utility of results (e.g. psychological benefits, benefits to other family members and future patients)	
Making sense: the emotional impact of results and information overload at the consultation meant that time was needed to process the implications of the results.	
Unmet needs: following the communication of results families often reported having unanswered questions and experiencing challenges in using the new information to improve their care, even when a diagnosis was confirmed.	
Feelings of guilt and blame: families' sense of responsibility about causing the patient's disability and/or passing on the conditions, which could be induced and/or exacerbated by the results	Communication at the point of testing: lack of openness and transparency about the reasons for testing, the different types of possible results and the impact on family's expectations
Service environment: insufficiently spacious offices for large families, lack of barrier free-access and child-friendly spaces	Communication about availability of results: issues related the communication to inform families that the results are ready, including lack of notice, provision of impartial information and/or long waiting times for appointment, lack of consultation on family preferences

Table 4 Priorities for improvement

Czech site	UK site
Health professional priorities	
Post-test care: follow up with families after results have been shared	Post-test care: facilitate communication after results have been shared (e.g. telehealth)
Family-facing educational and information materials: provide resources and content of the service website	Multidisciplinary collaboration: information that can be used by non-genetic professionals (e.g. at the point of testing)
Lab reports: improve accessibility by and utility for families	Lab reports: clear and standardised reports to improve accessibility by non-genetic professionals
Family priorities	
Post-test care: follow-up consultation	Communication at the point of testing: transparency and expectation management
Psychosocial support: involvement of psychologist and/or social worker at results delivery	Post-test care: support and advice after results are shared
Information provision	Post-test care: named point of contact
Manage feelings of guilt and blame	Communication about results availability
Improvement of service environment	Multidisciplinary care: better coordination between genetic and non-genetic professionals
Shared priorities	
Follow-up consultation	Communication at the point of testing: transparency and expectation management
Managing feelings of guilt and blame	Named point of contact for follow up
Environmental improvements	

Table 5 Quality improvement interventions at the two sites

Czech site				
Priorities for improvement	Post-test care	Managing feelings of guilt		Environment of the genetic service
Quality improvement interventions	Follow up consultation	Workshop on psychosocial aspects of communication process	Educational resources for clinical geneticists and families	Environmental improvements
Prototypes	<ul style="list-style-type: none"> Delivered by clinical geneticist who communicated the results Approximately 1 month after the initial communication of results For families who received a new diagnosis Information on psychosocial support (e.g. disease-specific and generic support groups) to be included in the report following the communication of results Families encouraged to prepare questions ahead of the follow-up consultation 	<ul style="list-style-type: none"> Focused on family's experience of guilt and self-blame in relation to the patient's disability and/or genetic findings Designed and delivered by clinical psychologists cooperating with the Czech Association of Rare Disorders Attended by 11 clinical geneticists from the service and 6 clinical geneticists from other services Clinical geneticists had the possibility to discuss relevant cases from their practice 	<ul style="list-style-type: none"> Purchase of relevant literature (e.g. the book by Dr. Ivana Fitznerová: "We Have a Disabled Child" (Portál, Prague 2010)). A total of 10-15 copies were made available at the service for health professionals and families The resource was recommended to all families with a child affected by a possible genetic disorder Families could borrow the book directly from the service 	<ul style="list-style-type: none"> Service staff designed a survey to gather the views of patients and families The survey was administered to all patients and families visiting the service over a period of one month Possible areas of improvement were identified, and priority was given to those that could be immediately addressed Changes included the provision of toys and the decoration in the waiting room to make it more child-friendly, and the provision of informational materials for patients and families.
UK site				
Priorities for improvement	Post-test care	Communication at the point of testing		
Quality improvement interventions	Named person for follow up and questions	Principles and recommendations to improve communication with families		
Prototypes	<p>Role profile:</p> <ul style="list-style-type: none"> Non-clinical role focused Based within the genomic service Sign-posting over the phone and face-to-face clinics Accessible through referral by health professionals and family self-referral <p>Duties and responsibilities:</p> <ul style="list-style-type: none"> Provide immediate psycho-social support Assess patients/families and sign-post them to specialist support, including genetic counselling and/or community services Liaise with genetic and non-genetic health professionals Compile and update database of available social and community services Patient advocacy, including attending consultations with families 	<p>Examples of principles and recommendations in relation to expectation management.</p> <ul style="list-style-type: none"> Principle: Avoid placing emphasis on "finding something" as this may increase families' expectations towards diagnosis. <p>Practical recommendations:</p> <ul style="list-style-type: none"> Be clear about the likelihood of getting a diagnosis. Normalise the situation: you can mention that many families do not receive a diagnosis and that support is available. Principle: Be open and transparent. <p>Practical recommendations:</p> <ul style="list-style-type: none"> Be clear about the difference the results could make. Be honest about what families can expect from a diagnosis and prepare them for the fact that in many cases little is known about the condition. Do not assume the family knows about rare diseases: be honest if you think the child has an undiagnosed genetic condition. 		

This is being corrected in this publication.

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