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Social media discourses on prenatal and newborn screening

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ABSTRACT

This study examines public discourses on prenatal testing and newborn screening on Facebook among Italian and German users from 2013–2023. Using a computational content analysis technique – specifically Structural Topic Modelling – we identify distinct discursive healthscapes that illustrate how digital biocitizenship is articulated in the context of reproductive health issues. The analysis reveals both shared concerns and culturally specific engagements across the two contexts. Key similarities include framing reproductive health as individual responsibility and ambivalence toward biomedical authority. Notable differences emerge in the politicisation of healthcare debates, approaches to de-medicalization, and the role of popular culture in shaping perceptions. The Italian corpus emphasises policy advocacy and critiques of healthcare commodification, while the German data focuses more on affective solidarity and awareness campaigns. Both contexts reflect tensions between demands for expanded screening and resistance to over-medicalization. Digital biocitizenship manifests differently when driven by organised advocacy versus individualised engagement. Overall, the findings illustrate how social media discourses on prenatal and newborn screening reflect broader sociopolitical tensions, while highlighting divergent pathways through which individuals navigate biomedical uncertainties by blending expert and experiential knowledge. This study contributes to understanding how reproductive health issues are constructed and contested in digital public spheres.

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Social media; topic modelling; digital biocitizenship; prenatal and newborn screening; reproductive health

1. Introduction and theoretical background

The internet has profoundly transformed the information environment, changing how laypeople interact with traditional knowledge authorities and epistemic institutions. This shift offers broad access to medical information and allows users to generate and share content across platforms. The health sector exemplifies these dynamics, particularly through the growth of online communities (Akrich, 2010; Vicari, 2021). These digital communities – often organised around specific health conditions, especially those

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characterised by medical uncertainty – have reshaped how individuals access, interpret, and at times challenge medical knowledge, thereby questioning traditional hierarchies between experts and laypeople.

This transformation aligns with sociological research on patient activism, which highlights the increasing role of non-experts in shaping and disseminating medical knowledge. From the early descriptions of 'popular epidemiology' (Brown, 1997) to the well-documented impact of AIDS activists in reforming biomedical research during the 1980s (Epstein, 1996), scholars have illustrated how patients and concerned publics have resisted expert dominance and demanded participation in setting research priorities and clinical standards. Patient involvement has taken various forms, including the co-production of experience-based knowledge, as well as the funding and development of independent studies (Brown, 2007; Crabu et al., 2022; Rabeharisoa & Callon, 2004). These actions – often seen as 'uninvited' or 'spontaneous participation' (Bucchi & Neresini, 2008) – have blurred the lines between lay and expert roles, giving rise to new hybrid figures like the 'experiential expert.' This has contributed to what Hess (2004) calls the 'public shaping' of medical research, where civic actors actively influence both the content and direction of biomedical inquiry.

In this framework, online communities and digital health platforms should not be seen merely as spaces for information exchange and support, but rather as infrastructures that accelerate and broaden patient mobilisation and epistemic activism. They reduce participation barriers, enabling a wider range of publics to engage in medical discourse (see Vicari & Ditchfield, 2024).

Against this backdrop, the case of newborn screening (NBS) as a mandatory public health measure, alongside the growing availability of non-mandatory prenatal tests, becomes particularly relevant. Within a contemporary model of child-centred care grounded in biomedical paradigms, NBS is framed as a crucial tool for promoting long-term health. It is positioned not only as a means of early diagnosis and intervention, but also as a way to influence future reproductive decisions and manage inheritable conditions. In recent decades, NBS has expanded rapidly in Western countries, often alongside non-invasive prenatal testing (Ravitsky et al., 2021). While prenatal tests aim to detect chromosomal abnormalities and congenital disorders, NBS uses predefined panels to identify treatable genetic conditions. Left untreated, many of these diseases can result in severe physical or neurological damage, intellectual disability, or even premature death. These programmes have significantly improved early detection and treatment (Nicholls et al., 2014). However, by extending biomedical scrutiny into the earliest stages of life, these programmes also produce new uncertainties and generate an urgent need for information among parents (Timmermans & Buchbinder, 2012). When a healthy-looking infant tests positive for a rare genetic condition, parents must quickly make sense of unfamiliar medical terms and risks. As a result, many turn to a variety of sources – including digital platforms – to seek out knowledge (Seale, 2002; Kallinikos & Tempini, 2014; Patterson et al., 2015). In recent years, digital health environments such as PatientsLikeMe, PicnicHealth, and patient communities on social media platforms like Facebook and X (formerly Twitter) have proliferated. These developments highlight the importance of examining how prenatal and newborn screening are embedded in real-world informational ecosystems and how digital media play a pivotal role in information access and emotional support (Araia & Potter, 2011; Lau et al., 2012; Zaslow, 2011).

This evolving informational landscape communicates specific messages about health and illness and serves as a central resource for acquiring what Rose (2006) calls 'somatic expertise' – knowledge and practices for managing one's body in relation to fields like genetics and reproductive medicine. Through these media, individuals share experiences and construct (lay) expertise that can challenge or reinforce the legitimacy of professional figures such as genetic counsellors and clinical geneticists, who function as 'pastoral experts' (Rabinow, 1996; Rose, 2006). These professionals help individuals and families understand and interpret the biomedical implications of their biological identity and their children's potential conditions. Thus, media not only facilitate the expansion of medical jurisdiction over the body but also participate in constructing complex discursive 'healthscapes' (Clarke et al., 2010; Crabu et al., 2021; Neresini et al., 2019). A healthscape refers to a multi-layered assemblage of individuals, institutions, technologies, expectations, and knowledges – both expert and experiential – that together shape how medical interventions are conceived, enacted, and either legitimised or contested. This concept is particularly useful for understanding the current phase of health platformisation (Miele & Giardullo 2024; Van Dijck et al., 2018), wherein digital media expand who participates in conversations around health and illness. Digital media facilitate the dissemination of biomedical knowledge, sometimes fostering understanding and other times inciting controversy – such as in the cases of gene therapy, cloning, or stem cell research. This dynamic pluralises the range of social actors – laypeople, companies, advocacy groups, and policymakers – who now shape health debates and influence public discourse (Allen et al., 2018; Hallin et al., 2013). In this context, people who are concerned with health and illness – whether personally affected or not – can actively mobilise health knowledge to understand disease, anticipate future conditions, improve caregiving, and communicate with professionals about therapeutic options (Weisgerber, 2004)

A notable feature of digital media is their affordance to connect users with personal narratives authored by patients and caregivers (Huisman et al., 2020; McCosker & Darcy, 2013). These stories offer alternative perspectives on illness, provide coping strategies, and support navigation through healthcare systems. They can be understood as performative narrative spaces that interrogate, reproduce, or contest dominant institutional models of health, while also serving to reduce uncertainty, make sense of biographical disruptions, and explore the intersection between lived experience and health knowledge (Mackintosh & Armstrong, 2020; Neresini et al., 2019), particularly in the context of rare diseases, genetic disorders, and chronic illnesses – conditions often marked by heightened uncertainty and disruption.

This study investigates how Italian- and German-speaking Facebook users have discussed prenatal and newborn screening over a ten-year period (2013–2023), analysing public posts to identify key themes and trace the emergence of distinct discursive healthscapes. Extending Clarke et al.'s (2010) broader conception of healthscapes – as the settings, actors, technologies, media, and cultural frameworks through which health is performed – we conceptualise the discursive dimension as the patterned ways in which health and medicine are understood, negotiated, and enacted through language and meaning-making in (digital) media environments. This allows for a nuanced analysis of how digital discourses – comprising imaginaries, narratives, values, and epistemic claims – shape public understandings of biomedicine in everyday life, linking technoscientific medicine with embodied experiences and sociocultural contexts.

Building on this empirical foundation, the paper explores how these evolving healthscapes afford diverse expressions of digital biocitizenship – a form of health-related civic engagement enacted through digital platforms (Elton, 2022; Rose, 2006; Vicari, 2023). Digital biocitizenship is conceptualised here as a contested biopolitical space, co-shaped by institutional actors and user-driven discourses that influence what knowledge is legitimised, what futures are envisioned, and what actions are rendered morally and socially acceptable. Digital media platforms thus emerge as dynamic arenas for negotiating biomedical authority, pluralising medical 'truths,' and embedding health knowledge within broader sociopolitical and affective landscapes. Unlike traditional biocitizenship, which often involves formal activism and institutional engagement, digital biocitizenship unfolds through everyday practices of sharing information, exchanging experiential knowledge, and mobilising around biomedical concerns in online environments. This framework enables a nuanced analysis of how digital discourses – comprising imaginaries, narratives, values, and epistemic claims – shape public understandings of biomedicine in relation to daily life. These discursive healthscapes link technoscientific medicine with embodied experiences, especially for expectant parents, newborns, and 'patients-in-waiting' (Timmermans & Buchbinder, 2010). Focusing on Facebook discussions, the study highlights how users actively construct and circulate meanings around prenatal testing and newborn screening, co-producing public imaginaries and normative frameworks concerning reproduction, risk, and care.

2. Research objectives and methodological framework

Both prenatal testing and newborn screening aim to shorten the time during which a child may be ill without a diagnosis. When effective, they enable early diagnosis and treatment, preventing long and distressing 'diagnostic odysseys'. Yet, when results are ambiguous, they may trigger new forms of uncertainty for families, initiating complex interpretive and emotional journeys. Social media platforms such as Facebook have become key spaces where users share experiences, exchange information, and make sense of such early-life medical interventions. This paper investigates how prenatal testing and newborn screening are discussed online, focusing on the types of information circulated and the forms of engagement they foster. While these practices differ institutionally and ethically, they often appear together in online discourse, suggesting a continuum of biomedical concerns. We therefore ask: *How do the evolving discursive healthscapes surrounding prenatal tests and newborn screening afford instances of digital biocitizenship on social media?*

In discursive healthscapes, the expanding scope of biomedical scrutiny from the early days of individuals' lives, or even before birth, can be seen as encompassing much more than specific, separable dimensions, such as family, religious beliefs, economic interests, policies and media. Instead, healthscapes attempt to capture all these elements together, considering the types of discursive assemblages (including people, practitioners, expert and experiential knowledge, technologies, expectations and places) that are shaped within social media informational flows.

We collected Facebook posts from Italian- and German-speaking communities using specific keywords related to prenatal testing and newborn screening from the

CrowdTangle platform[1] (CrowdTangle, 2023), which allowed us to download the posts of public pages, groups and verified profiles.

Although our analysis draws on Italian- and German-language content, our aim was not to conduct a systematic comparison between these linguistic or national contexts. Rather, the two corpora served as entry points for analysis to identify both shared and divergent discursive patterns in how prenatal testing and newborn screening (NBS) are discussed on social media, across different sociocultural and healthcare environments. The decision to focus on these two linguistic domains was guided by the presence and density of relevant online discussions, as well as the specific configurations of reproductive health discourse in each setting. The Italian corpus primarily reflects conversations within the Italian national context, while the German-language corpus includes posts from Austria, Germany, and the German-speaking regions of Switzerland. These areas share a common language and similar healthcare structures, allowing us to build a coherent dataset across multiple national settings. Notably, the welfare and healthcare regimes in Austria, Germany, and German-speaking Switzerland differ significantly from the Italian model, which is characterised by a strong familistic orientation (Furfaro et al., 2024). Italian and German are also among the most widely spoken languages in Europe, enabling the construction of two robust corpora comparable in volume and interaction density.

We used Boolean logic to collect posts containing the chosen keywords within the timeframe of February 2013 to February 2023.[2] As a result, we were able to construct two large datasets, providing detailed data on the content and types of job postings related to prenatal tests and newborn screening. After removing duplicates, we obtained 8075 posts in German and 8282 in Italian. All data made available by CrowdTangle and analysed in this paper pertain to public Facebook pages and profiles. The data do not include information regarding comments or other elements that could violate users' privacy or confidentiality. The ethical considerations surrounding the use of digital traces in social research prompt a return to the golden rule of 'do no harm' (Barbosa & Milan, 2019, p. 57). This implies that researchers should take care to protect the subjects under study, regardless of the public nature of the space. Accordingly, when necessary and relevant, we applied de-identification techniques to replace all identifying information with pseudonyms while preserving the analysability of the data.

The analysis employs topic modelling via a Structural Topic Model (STM; Roberts et al., 2016). Compared with other topic-modelling approaches, STM offers several advantages: it relaxes the assumption of topic independence, enabling the detection of correlated thematic structures, and it allows document-level covariates to be incorporated directly into the estimation process. This capability makes it possible to examine how specific metadata – such as time, user characteristics, or platform context – influence topic prevalence and content. The primary drawback of STM is its computational intensity, particularly when estimating parameters related to topic prevalence, content variation, and document – topic associations. A more general limitation of topic modelling is that topics are not automatically labelled, requiring researchers to manually interpret and name them, thereby introducing subjectivity. STM also demands careful tuning of parameters such as the number of topics (k). In our case, the use of the CD score reduced the number of topics compared with other diagnostics that measure predictive accuracy, such as held-out log-likelihood and residuals (see Supplementary

Materials, Fig. S1). Consequently, the number of topics analysed reflects a human judgement more than a purely statistical optimisation. While Semantic Coherence and Exclusivity metrics provide useful guidance, they remain insufficient on their own; human interpretation remains essential for validating topics.

First, we removed Italian and German stop words and selected words that appeared at least 10 timexs. To determine the best number of topics, we used semantic coherence and exclusivity diagnostics combined with the Consistency and Differentiation (CD) score (AUTH). The CD score calculates the L_2 norm of two min – max normalised measures to synthesise the trade-off between semantic coherence and exclusivity. According to the CD score, the ideal number of topics was 11 for the Italian dataset and eight for the German dataset. The STM model includes a covariate indicating the year in which each Facebook message was posted. In this way, topics are also determined by the influence of the moment the posts were written along a 10-year timeframe. To account for the effect of time, we applied smoothed function (B-spline with 4 degrees of freedom) normalisation to the 'time' variable to detect nonlinear relationships. All the topics, including the top 15 words (i.e., the words with the highest probability for each topic) and the top 30 documents (i.e., the posts with the highest probability of belonging to a topic), were manually scrutinised.[3]

The relevant topics (see Tables 1 and 2) were selected based on the following three criteria, defined according to the previously detailed research question: (i) explicit reference to newborn healthcare, disease and illness issues; (ii) explicit reference to technologies and programmes for prenatal tests and newborn screening; and (iii) explicit reference to biomedical research and medical technologies addressing genetic and metabolic pathologies in newborns.

Following these three criteria, we conducted a level-one review to interpret the topics (i.e., the top 15 words and top 30 documents) and select those pertinent to our research purpose by scrutinising their content following a thematic analysis approach (see Riger & Sigurvinsdottir, 2016). After this initial review, we performed a more complex second-level review by analysing the topics according to a logic combining internally homogeneous but externally heterogeneous topics into insightful healthscapes, aiming to trace and examine emerging discursive instances of digital biocitizenship across the two corpora. As a result, some topics, though internally homogeneous but externally heterogeneous, contributed to the same discursive healthscape due to the nature of the emerging discourses, which enacted a distinct and well-defined instance of digital biocitizenship (e.g., the *Public advocacy and stakeholders' engagement in the context of prenatal tests and newborn screening* discursive healthscape in Table 1). In other cases, however, a single topic delineated a well-defined healthscape. This approach aligns with the diagnostics (i.e., CD score) used to determine the ideal number of topics, as we maximised both (i) semantic coherence (i.e., the words most probable under a topic should co-occur within the same document) and (ii) exclusivity (i.e., the degree to which words are exclusive to a single topic; see also the supplementary materials).

These two levels of review served to demonstrate that a topic, or more than one, was appropriate for informing a healthscape and that a healthscape was appropriate for informing the interpretation of the dataset. Given the paper's focus, the presentation of findings follows an argumentative strategy in which the relevant topics serve as empirical triggers to explore and theoretically capture how discursive healthscapes on prenatal

Table 1. Discursive healthscapes, related topic and main claim makers: the Italian-speaking corpus.

Discursive healthscape	Topic	Top seven keywords	Main claim makers engaging in posting activities	Examples of top-ranked post per topic
1_Public advocacy and stakeholders' engagement in the context of prenatal tests and newborn screening	Topic 1	Hospital, near, centre, prenatal, gynaecology, diagnosis, obstetrics	– Facebook profiles (public pages, groups) managed by civic associations at the urban/regional level – Official profiles of scientific associations and a medical observatory – Official profiles of patients' associations	**Topic 1:** *Many small drops make the ocean; many small donations support research! Support ANF, the Association for Neurofibromatosis (Odv) in Parma. It costs you nothing, but it helps us a lot – a simple gesture that will warm your heart! The term neurofibromatosis refers to at least seven different genetic disorders, all characterized by the presence of benign tumors that develop along the nerves*
	Topic 3	Screening, neonatal, diseases, extended, metabolic, tests, AISMME[a]		**Topic 3:** *#ExpandedNewbornScreening PROTECT THEIR FUTURE WITH EXPANDED METABOLIC NEWBORN SCREENING. Prevention is where their future begins. A simple test – a small blood sample taken from the baby's heel between the 48th and 72nd hour of life – can enable the early identification of around fifty serious and otherwise difficult-to-diagnose genetic metabolic disorders* […].
	Topic 5	Screening, neonatal, diseases, rare, project, SMA[b], association		**Topic 5:** *The presentation of the storybook 'Wolf Tells the Story of SMA', an editorial project on spinal muscular atrophy, will be held on Monday, May 17 at 11:00 AM. On this occasion, a previously unpublished story about newborn screening will also be presented.* […]
	Topic 7	Being, children, can, diagnosis, age, cases		**Topic 7:** *What is hip dysplasia? Hip dysplasia is a joint deformity that begins during the baby's intrauterine life but continues to develop during the first years after birth. This understanding has led to the abandonment of the old term 'congenital hip dysplasia.'*
2_Supporting prenatal diagnosis and mother caregiving for children with genetic diseases	Topic 2	Life, being, when, to do, only, mom, done	– Facebook profiles (public pages, groups) managed by civic associations at the urban/regional level	**Topic 2:** *WORLD CONGENITAL HEART DEFECT AWARENESS DAY: Every year on February 14, Valentine's Day – a holiday symbolically associated with the heart – World Congenital Heart Defect Awareness Day is celebrated. […] It is therefore clear how important early diagnosis is, ideally starting during the*

(*Continued*)

Table 1. Continued.

Discursive healthscape	Topic	Top seven keywords	Main claim makers engaging in posting activities	Examples of top-ranked post per topic
				prenatal period, in order to provide appropriate family counseling […]
3_Scrutinising public policies and politics on neonatal screening	Topic 6	Diseases, law, screening, rare, neonatal, health, today	– Facebook profiles (public pages, groups) of civic associations supporting the Five Star Movement[c]	**Topic 6**: *281 amendments from the Five Star Movement (M5S) have been submitted to the budget law currently under discussion in Parliament. […] On the healthcare front, we have put forward a series of proposals, ranging from funding for the autism support fund – directly benefiting families – to the extension of newborn screening to include diseases that allow for early diagnosis*. […]
4_Commodification of prenatal and newborn health	Topic 8	Test, prenatal, pregnancy, diagnosis, foetal, foetus, screening	– Facebook profiles (public pages) of private medical clinics and laboratories offering prenatal tests and newborn screening	**Topic 8:** *PRENATAL DIAGNOSIS | THE NEOBONA TEST – A MODULAR OFFERING FOR EVERY NEED It is the new generation of non-invasive prenatal testing (NIPT). Performed on a maternal blood sample, it assesses the risk of the most common trisomies and other fetal chromosomal abnormalities through the analysis of cell-free DNA. It is a fast (results available in 10 working days), accurate test.* […]
5_Demedicalising prenatal and newborn medicine through holistic approaches	Topic 10	Radio, treatment, Pietrangeli[d], Massimo[17], physician, web, medicine, method	– Facebook profiles (public groups) disseminating information and knowledge on holistic approaches and alternative and complementary medicines for healing and well-being	**Topic 10:** *Massimo Pietrangeli – Pediatrician, Homotoxicologist, Holistic Doctor, Allergist, Neonatologist, and Professor at the University of Chieti, where he teaches Functional Medicine in Pediatrics. He conducts self-care courses using the CDS Method, as well as classes in Infant Water Activities, Prenatal Training, and Water Birth Preparation with Watsu and Shiatsu techniques.*

[a]AISMME is the abbreviation for Associazione Sostegno Malattie Metaboliche Ereditarie [Association for Support of Hereditary Metabolic Diseases].
[b]SMA is the abbreviation for Spinal Muscular Atrophy.
[c]The Five Star Movement (*Movimento 5 Stelle* – M5S) is an Italian political party known for its populist stance and direct democracy principles. Founded by comedian Beppe Grillo in 2009, it advocates for anti-corruption, environmentalism and digital democracy. It has gained significant support through its online platform and grassroots activism, becoming a major force in Italian politics, with varying success in national elections.
[d]The keywords 'Pietrangeli' and 'Massimo' refer to Massimo Pietrangeli, a prominent Italian pediatrician known for supporting the adoption of holistic approaches in the context of allopathic medicine.

Table 2. Discursive healthscapes, related topic and main claim makers: the German-speaking corpus.

Discursive healthscape	Topic	Top seven keywords	Main claim makers engaging in posting activities	Examples of top-ranked post per topic
1_ Public advocacy for rare diseases and blood donation	Topic 3	children, illnesses, rare, parents, families, illness, affected	– Facebook profiles (public pages, groups) managed by a Switzerland-based civic association reaching out across Germany, Austria and Switzerland to raise funds for families in need – Facebook profiles (public pages, groups) managed by local news media and public websites	**Topic 3:** *Rare diseases in the media – Our work has an impact! Only if we have a media presence, provide information, educate and raise awareness, we can create a better social and political understanding of rare diseases. […] We support affected families financially (around 1.4 million since 2014), organize wonderful KMSK[a] family events (for around 6,000 family members since 2014) to connect them and anchor knowledge on the topic of 'Rare diseases in children' among specialists and in the public*
	Topic 5	that, life (also to live), more, always, child, indeed, at times		**Topic 5:** *TODAY please donate blood. 12 percent of blood donations are needed for the treatment of injuries following accidents. The German Red Cross Blood Donor Service is therefore calling for blood donations. […] Active blood donors helped to save Friederike Streckenbach, when she lost several litres of blood a few days after the birth of her daughter Ida due to bleeding in her uterus.*
2_Understanding genetic screening and rare diseases through popular culture	Topic 6	prenatal testing, women, earth, pregnancy, down's-syndrome, disability, trisomy was, that, our, were, often, could, first	– Facebook profiles (public pages, groups) managed by Kindle readers to share book recommendations and reviews – Facebook profiles (public pages, groups) managed by reading groups to share book recommendations and reviews	**Topic 6:** *Project Optarmis: Ascension Children whose parents have the ideal genetic make-up for professor Bergström's medical experiments are prepared for their future tasks after birth in a remote camp. With painful medical modifications and tough military drills, they are to be lent to wealthy clients after completing their training. For these clients, they will then work either as assassins or bodyguards*
	Topic 7			**Topic 7:** *Today Shanna understood her vision of the devilish face of Lord Corran van Diac better. The priests would have considered it a gift that she could have trained in the priestly caste! Among the Atlantean people, such diseases were accepted differently than in the human world.*

(*Continued*)

Table 2. Continued.

Discursive healthscape	Topic	Top seven keywords	Main claim makers engaging in posting activities	Examples of top-ranked post per topic
3_ De-medicalising pregnancy and birth	Topic 8	birth, child, mother, always, woman, pregnancy, clear	– Facebook profiles (public groups) publishers disseminating information and knowledge on homeopathy and alternative medicine	**Topic 8:** *Most women describe this phase as the most beautiful and joyful of their lives. […]Pregnancy itself is not an illness and should not be regarded as such by homeopaths. […] Birth in particular – with or without complications – often has a traumatic effect on mother and child. Appropriate homeopathic follow-up treatment can alleviate early traumatic experiences and thus be beneficial for the child's future life*

[a]KMSK is the German apprivation for 'Kinder mit seltenen Krankheiten' (children with rare diseases)

tests and newborn screening shape and orient specific instances of digital biocitizenship, particularly in managing the human reproductive sphere.

3. Findings

3.1. Overview of the Italian-speaking corpus

From our analysis of the Italian-speaking corpus, we identified five different discursive healthscapes around which the posting activities were organised (see Table 1).

Generally speaking, these healthscapes – while specifically cantered on newborn screenings, prenatal tests and reproductive decision-making processes – align with the main constitutive dimensions of contemporary public narratives about biomedicine, health and illness in general (see Hallin et al., 2013) – namely: (i) health and well-being viewed as responsibilities that require individuals to engage in self-monitoring and self-surveillance (see discursive healthscapes 1 and 5); (ii) biomedicine seen as an extensive technoscientific endeavour, arising from the complex interactions between various research domains and their technological applications (see discursive healthscape 2); and (iii) national healthcare policies debated in the context of non-expansionary fiscal policies and austerity measures in state budget management (see discursive healthscapes 3 and 4).

The first discursive healthscape, composed of Topics 1, 3, 5, and 7, reflects posts centred on public advocacy and the active engagement of stakeholders with prenatal and newborn screening. In this context, posting activities aim to generate public pressure on medical institutions, driven by the demands of patients and advocacy groups for the widespread implementation of prenatal testing and the promotion of newborn screening programmes. This mobilisation also calls for increased funding and support for scientific research focused on identifying the genomic basis of early-onset diseases, as well as the development of effective screening protocols and therapeutic interventions. At the core of this discursive healthscape lies the belief that uncovering a biological substrate for disease expands the possibilities for timely and targeted intervention, reinforcing a vision of health rooted in early detection and biomedical innovation. It is within the realm of probabilities, predictions and preventive interventions that this discursive healthscape is articulated, framing the act of posting as a form of digital biocitizenship aimed at raising awareness about the importance of prenatal tests and newborn screening in managing and addressing rare metabolic or genetic diseases.

This first discursive healthscape goes beyond reflecting well-established citizen activism concerning health and illness within the context of reproductive decision-making. Here, patient organisations and support groups aim to shape and enhance direct partnerships with scientists who participate in posting activities through the Facebook profiles of scientific associations within the healthscape under scrutiny. These patient organisations and support groups not only sustain fundraising campaigns for biomedical research on congenital disorders and hereditary metabolic diseases but also strive to influence the direction of biomedical research. For example, they may request more research on under-researched pathologies, such as neurofibromatosis. Their goal is to accelerate the development of cures or treatments amid recent advancements in genetics and neuroscience. Therefore, these claim makers engage in biomedical activism to directly

impact the knowledge and technologies stemming from biomedical research. This form of digital biocitizenship depends on current scientific advancements while also fostering hope for future breakthroughs in treatments or cures. Thus, rather than merely wishful thinking and anticipation, this discursive healthscape proposes a vision of a desirable future that requires present-day actions to be achieved. This aspect reflects the current mainstream form of patient activism, which revolves around a 'collaborative model' (Rabeharisoa, 2003). This model sees patients as promoters of scientific research on their own conditions, effectively establishing a more balanced distribution of decision-making power between experts and non-experts regarding the implementation of biomedical research and the definition of therapeutic protocols.

The second discursive healthscape, labelled Supporting prenatal diagnosis and mother caregiving for children with genetic diseases, is composed of Topic 2 and concerns an effort to disseminate knowledge and information supporting the relevance of adhering to prenatal and early diagnosis screening programmes to ensure a better quality of life for newborns with rare genetic diseases. This discursive healthscape also emphasises the mother's role as a 'natural' caregiver, highlighting the difficulties a mother faces in managing an adverse prenatal diagnosis. Here, the terms 'parenthood' and 'caregiving' are predominantly associated with the mother, discursively naturalising her as the figure bearing the greater burden of managing the care of the child. It is important to emphasise that a specific instance of biocitizenship concerns the pressure placed on women, who are portrayed as 'natural subjects' and are expected to take responsibility, even genetically, for the well-being of their children. This instance is deeply embedded in the gendered division of reproductive and affective labour. Within this frame, claim makers promote an informed gendered ethics of the self – a set of techniques grounded in expert biomedical knowledge for managing everyday life in relation to pathological conditions detectable through newborn screenings and prenatal tests. In many posts, mothers are outlined as pivotal actors within the family, invoking images of care for newborns as a haven of affection. Families are depicted as synonymous with love and care, with mothers as inherently natural caregivers. This discursive healthscape refers to mothers as subjects subsumed to a moral obligation for caregiving, thereby reinforcing hegemonic masculinity in the sexual division of reproductive labour within the family. This often invokes alleged maternal feelings of love and affection to explain their caregiving for newborns with rare congenital diseases.

The third discursive healthscape (Examining public policies and politics on neonatal screening) is composed of Topic 6, which focuses on the current Italian policies regarding newborn screening programmes. This healthscape addresses issues concerning the social implications and benefits arising from newborn screening programmes in relation to the healthcare system's structure. It discusses the role of public institutions in Italy, particularly at the regional level, in supporting the extension of mandatory newborn screening programmes. Many posts specifically highlighted the role of the Italian political party MoVimento 5 Stelle [i.e., 5 Star Movement] in neonatal care as a social development objective. This discussion occurs within the broader discursive framework of this third healthscape, portraying Italy as an exemplary country in terms of public policies on neonatal screening. Italy extended free screening in 2016 to all newborns for 40 rare genetic metabolic diseases that are treatable but require timely diagnosis.

The fourth discursive healthscape (Commodification of prenatal and newborn health) is composed of Topic 8 and concerns posting activity advertising the selling of prenatal diagnostic screening and other genomic diagnostic tests by private companies and clinics. Hence, this discursive healthscape is deeply configured within the current economic vital circuits embedded in a capitalist culture (Ducournau et al., 2013). Therefore, the postings within this discursive healthscape are concerned with the services offered by private prenatal testing and newborn screening providers, portraying newborn health as both an economic commodity and a moral obligation for parents or future parents. In this way, this discursive healthscape shapes a commercial dynamic by commodifying prenatal testing and screening, thereby influencing social expectations of health by promising to provide 'premonitory knowledge' (Lock, 2005) aimed at foreseeing and addressing the potential future outcomes in a newborn's life. These anticipations of the future, even when uncertain and probabilistic, entail responsibilities to take immediate action concerning one's own health, body and well-being in light of these potential outcomes. In line with the ongoing biomedicalisation process, this discourse reflects the current restructuring of state powers regarding health and illness issues, with responsibilities for managing human health and reproduction increasingly delegated to private corporations – such as fertility clinics and biotechnology companies – that sell products, such as genetic tests, directly to consumers.

The fifth healthscape is composed of Topic 10 and concerns posting activity that generates 'public pressure' driven by a call for de-medicalising the human reproduction sphere and newborn health management at large. Here, the claim makers engage in a contentious relationship with the conditions under which biomedical knowledge is shaped and mobilised in the context of newborn and mothers' health. In so doing, they do not merely highlight a supposed medicalisation trend that would harm people's health. In their attempts to publicly demonstrate the relevance of adopting an alternative model of healing, such as methods encompassing holistic medicine and caring for the sake of individuals and society at large, claim makers generally adopt an adversarial relationship with scientific communities and medical practitioners. Hence, what lies at the centre of this discursive healthscape are claims to the right to other forms of knowledge in the approach to the human psychological and biological condition, as shown by the growing consensus on alternative models of caring and healing among both ordinary people and communities of health professions. In this discursive healthscape, the relevance of prenatal tests and newborn screening is questioned because they are seen as drivers that contribute to defining health as a goal that can be achieved exclusively through technological means. It is, therefore, a critique of a supposed biomedical reductionism that encourages people to rely increasingly on drugs and medical technologies. Hence, this discursive healthscape highlights that while scientific biomedicine has succeeded in establishing its epistemic authority and moral force in the public understanding and management of health and illness issues, thereby acquiring broader cultural, political and administrative significance, medical developments are not a 'technological tsunami' that erases alternative practices and cultures. On the contrary, the meanings and emerging practices surrounding prenatal tests and newborn screening are negotiated in diverse ways, including in media contexts where resistance and other counter-knowledges and beliefs can emerge or fade from the foreground of mainstream media discourses.

3.2. Overview of the German-speaking corpus

In examining the selected topics in the German-speaking corpus, we identified four relevant topics (see Table 2) that pertain to three different discursive healthscapes.

The first discursive healthscape, 'Public Advocacy for Rare Diseases and Blood Donation', comprises Topics 3 and 5. The main claim makers in this space are patient communities and networks of families affected by rare diseases (e.g., Kinder mit seltenen Krankheiten [Children with Rare Diseases]), alongside various Facebook profiles (public pages and groups) managed by civic associations at the urban or regional level (e.g., Eb-Heim-City; Calw – Informationen und News aus dem Kreis; Altensteig und drumrum). While these latter profiles primarily promote blood donation, both prenatal testing and newborn screening are discursively framed within broader appeals for solidarity around rare diseases. Mobilising personal narratives, these posts encourage public engagement, voluntary action, and financial support. In Topic 3, particularly, patient communities issue a kind of digital 'call to arms' for children with rare diseases – foregrounding activism as a form of biodigital citizenship, where civic identity and engagement are reshaped around genetic conditions and their visibility in digital publics. The posts highlighted how it is possible to improve the public and political understanding of rare diseases by being present in the media sphere, where it is possible to improve health literacy and sensitise people to the wider social implications of affected families. In addition, posts often discussed the challenges that families with newborns diagnosed with rare diseases are expected to face using personal stories (e.g., the story of a girl diagnosed with cancer and her parent's journey through her final days) to encourage financial donations to associations such as 'Kinder mit seltenen Krankheiten', supporting their public advocacy and aiding affected families. In Topic 5, local city communities, predominantly in Germany, lead the public advocacy efforts. They use posts to explain the significance of blood donations, often featuring personal stories, such as the account of a woman whose life was saved by blood donations after she lost a significant amount of blood during childbirth and the story of a child who donated blood to her ill sister.

The second discursive healthscape identified is 'Understanding genetic screening and rare diseases through popular culture', encompassing Topics 6 and 7. In this regard, it is important to note that the claim makers involved engage with issues such as genetic screening and rare diseases using popular narratives. Indeed, in Topic 6, several Facebook profiles of reading groups (e.g., buch und Lesen [Book and Reading]; Der Lese-Klub [The Reading Club]) share book reviews of sci-fi narratives, discussing issues related to genetic optimisation of children who undergo extensive training and modifications for future roles as assassins or bodyguards. Issues such as abortion (foetus selection), trisomy, Down syndrome and disability are linked to the broader scope of the genetic optimisation discussed in science fiction stories (see the keywords in Table 2). It also reveals how prenatal and newborn screening are perceived by the German-speaking public on Facebook, intertwined with dystopian concepts of eugenics, genetic optimisation and human enhancement.

In Topic 7, the use of popular literary genres continues in relation to rare disease experiences. Online reading groups shared reviews of a story about Shanna, a girl from a small village in South Dakota. Her initial illness symptoms bring suffering, although to the Atlantean people, unlike humans, her illness is seen as a gift. In this

context, prenatal tests and newborn screening are not explicitly addressed but are implicitly explored through broader themes in popular literature, including genetic optimisation and the subjective experiences of illnesses. The discussed fictional literature especially draws on the motives of social exclusion and discrimination associated with biological variation and notions of deviation. This discursive healthscape underscores the role of popular culture in facilitating the public's understanding of complex issues, especially when they are not widely familiar.

The third healthscape, 'De-medicalising pregnancy and birth', relates to Topic 8. Here, prenatal tests and newborn screening are framed within the broader context of pregnancy and birth. The text posted by groups promoting alternative medicine, especially homeopathy (e.g., Verlag Homöopathie [Homeopathy Publishing] and Gruppe Alternative Medizin [Alternative Medicine Group]), emphasises pregnancy and birth as special moments requiring attention. These groups frame pregnancy, birth and parenthood not only as vulnerable but also as special and precious periods of life that require special care, suggesting that homeopathy can offer support to people dealing with them. This healthscape emphasises the gendered and biomedicalised nature of the human reproductive sphere, addressing the psychological and social issues that may affect mothers and their potential impact on unborn children. Consequently, alternative medicine groups in this domain advocate for the de-medicalisation of pregnancy and birth, focusing on the mother's psychological well-being and her role in the child's development, while framing prenatal tests and newborn screening – typically associated with technoscientific medicine – as undesirable policies. Hence, they highlight the importance of maternal and foetal well-being outside the conventional biomedical framework. These groups advocate for a de-medicalised approach to birth and pregnancy, promoting practices such as water births or home births, where the focus is on the well-being of the mother and newborn without necessarily relying on biomedical advice.

4. Discussion and concluding remarks

This study examines public discourses on prenatal testing and newborn screening on Facebook among Italian and German users from 2013 to 2023. Genetic testing technologies present complex challenges for prospective parents, particularly when an infant tests positive for a rare disorder. Increasingly, parents turn to digital spaces to seek and share health-related experiences. These online environments, where users navigate and sometimes contest biomedical interventions in reproduction, offer rich data for studying digital biocitizenship – a phenomenon that has expanded significantly, enabling individuals to access and disseminate health information about themselves and their families (see Agodi et al., 2023; Brosnan et al., 2018; Neresini et al., 2024; Prainsack, 2017). Our analysis reveals distinct yet overlapping discursive healthscapes in the Italian and German corpora, reflecting both shared concerns and culturally specific engagements with prenatal testing and newborn screening. A key similarity across both contexts is the framing of reproductive health as a matter of individual responsibility, where prospective parents feel morally compelled to utilise all available medical and alternative interventions to safeguard their child's health. This underscores a broader shift toward digital biocitizenship, in which individuals are expected to actively manage their health

through self-monitoring, advocacy, and the integration of diverse knowledge systems – ranging from biomedicine to holistic practices.

However, notable differences emerge in how these discourses are articulated. In the Italian-speaking corpus, discussions are more explicitly politicised, with strong emphasis on public healthcare policies, regional disparities in service provision, and critiques of the commodification of reproductive medicine. For instance, discursive healthscapes in the Italian data include advocacy for expanded newborn screening programmes (e.g., healthscape 3) and critiques of privatised prenatal testing (healthscape 4), often tied to broader debates about austerity and the erosion of public healthcare. In contrast, the German-speaking corpus exhibits a more pronounced focus on affective solidarity, public awareness campaigns, and the role of popular culture in shaping perceptions of genetic screening. For example, healthscape 1 in the German data highlights blood donation drives and personal narratives of rare disease experiences, while healthscape 2 engages with dystopian literary tropes to interrogate ethical dilemmas around genetic optimisation.

Another divergence lies in the gendered dimensions of care. While both corpora reinforce traditional notions of maternal responsibility, the Italian data more explicitly ties caregiving to a moral obligation for women, often naturalising their role as primary caregivers (healthscape 2). The German corpus, meanwhile, critiques the biomedicalization of pregnancy (healthscape 3) but does so through advocacy for alternative medicine, framing de-medicalization as a means of reclaiming autonomy rather than reinforcing gendered norms.

Despite these differences, both corpora reflect an ambivalent relationship with biomedical authority. In Italy, this ambivalence manifests in tensions between demands for state-supported healthcare and the proliferation of privatised genetic testing. In Germany, it appears in the juxtaposition of biomedical advocacy (e.g., rare disease activism) with skepticism toward technoscientific interventions (e.g., homeopathy groups rejecting prenatal screening). This duality highlights how digital biocitizenship operates within a contested terrain – where social media platforms simultaneously facilitate the commodification of reproductive health (through targeted ads from private clinics) and provide spaces for resistance (through activist critiques and alternative health movements).

Crucially, our findings reveal that digital biocitizenship is not monolithic. In contexts where social media engagement is driven by organised advocacy (e.g., Italian patient groups lobbying for policy changes or German rare disease networks), it fosters collective action and systemic critiques. Conversely, when engagement is more individualised (e.g., German users sharing personal stories or literary reflections), it tends to prioritise emotional support over structural critique. This distinction underscores the role of platform affordances in shaping discursive outcomes: while Facebook enables both market-driven health commodification and grassroots mobilisation, the latter often requires coordinated efforts to translate affective engagement into tangible policy impacts.

Overall, this study shows how prenatal testing and newborn screening discourses on Facebook reflect broader sociopolitical tensions surrounding reproductive health. The Italian and German cases illustrate divergent pathways through which digital biocitizenship emerges – ranging from politicised healthcare debates to culturally mediated ethical reflections. Yet both contexts share a growing expectation that individuals will assume

responsibility for navigating biomedical uncertainties, often blending expert and experience-based knowledge systems (Andalibi et al., 2017; Hussain & Alhabash, 2021).

Notes

1. CrowdTangle, developed and released by META, was a social media monitoring and analytics platform that tracked the spread of content across platforms like Facebook. It was primarily used by researchers to identify trending stories, measure engagement and monitor public conversations. As of August 2024, the platform is no longer actively operational.
2. We present below the queries used to collect posts, translated into English but originally formulated in Italian and German, to ensure that we capture the respective linguistic nuances. Queries (the comma corresponds to the Boolean operator OR; a set of words placed in quotation marks means the exact phrase):

    - newborn testing
    - newborn screening
    - rare disease screening AND (boy, girl, boys, girls, child, children)
    - hereditary disease testing AND (child, children, boy, girl, boys, girls, newborn, newborns, neonatal)
    - congenital disease testing AND (child, children, boy, girl, boys, girls, newborn, newborns, neonatal)
    - prenatal AND (diagnosis, diagnostics, screening) OR ('genetic test' AND (fetus, unborn child, embryo)

3. The corpora were analysed by the authors in their original language. The English translations of the top seven keywords and the top-ranked post for each topic were carried out by the authors themselves (see Tables 1 and 2). These translations are provided in the paper to offer a comprehensive and empirically illustrative presentation of the findings that emerged from the analysis.

Contribution statement

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Barbara Morsello: Conceptualization (supporting); methodology (supporting); writing – original draft (supporting); data curation (supporting); formal analysis (supporting); editing (supporting).

Federico Neresini: Conceptualization (co-lead); methodology (supporting); writing – original draft (equal); data curation (supporting); formal analysis (supporting); editing (supporting).

Andrea Sciandra: Conceptualization (equal); methodology (lead); writing – original draft (equal); data curation (lead); formal analysis (lead); editing (supporting).

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No potential conflict of interest was reported by the author(s).

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