

# Newborns' Moral Right to Genomic Ignorance Foundations – Conceptualisation – Implications



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## (1) Introduction

- **Background: Debates on right to genomic ignorance focus on genetic testing of a) adults** (Knoppers JLME 2014; Dive J Med Philos 2021) **b) children with family history for adult-onset diseases** (Robertson/Savulescu Bioethics 2001), **but not of c) healthy children as targeted by population-wide newborn screening:**

“ such a right has not played a significant role in discussions of public health newborn screening practices historically, as those practices have been aimed at immediately relevant, rather than adult-onset, conditions. (Morrissey/Walker J Med Philos 2018, 30f.) ”

- **New developments: Several research studies on genomic newborn screening (gNBS)**

- Sequencing newborns' genomes
- Including healthy newborns without family history for genetic diseases; sometimes screening for adult-onset diseases
- Examples: in USA "GUARDIAN study", "BabySeq", ...; in UK "Generation Study"; in Belgium: "Baby Detect"; across EU: "Screen4Care"; ... (Stark/Scott Nat Rev Genet 2023)

- **Goal & Methods: Our research project NEW\_LIVES (Genomic NEWborn screening programs – Legal Implications, Value, Ethics and Society) <http://gnbs.ukhd.de>**

- Normative framework for potential future gNBS program in Germany (including: selection criteria for target diseases)
- Inter- + transdisciplinary methodology: bioethics, law, medical psychology, human genetics, pediatrics/newborn screening lab, patient representatives; methods of this poster: normative applied ethics, theory of rights, Hohfeldian analytical system (Hohfeld Y.L.Y. 1913)

- **Questions:**

1. Do newborns targeted by gNBS (asymptomatic, no family history for genetic diseases) hold a right to genomic ignorance?
2. What are the implications of this right for population-wide gNBS (esp., may gNBS include screening for late-onset diseases)?

## (2) Foundations of right to genomic ignorance

### Adults' right to genomic ignorance:

- in our view based on autonomy (cf. e.g. Andorno J Med Ethics 2004)
- right to genetic self determination
- right to know
- right not to know
- = right to make well-informed decisions about whether to know or not to know own genetic information, i.e. ...

“ ... Autonomie heißt dann, über die Informationen, die man seiner Entscheidung zugrundelegen will, selbst zu bestimmen – es heißt nicht, unter optimaler Information zu entscheiden. (Siep 1995, 327. In: Beckmann: Fragen und Probleme einer medizinischen Ethik) ”

### Young children's (future) right to genomic ignorance:

- in our view based on child's best interest, which includes **(future) autonomy** – associated duty to protect (future) autonomy (cf. Borry et al. JLME 2014; Schickhardt Kinderethik 2012)
- **(future) right to genetic self determination**
- **(future) right to know**
- **(future) right not to know**

“ The future autonomy of the child may outweigh the autonomy of parents in this context and might justify the withholding of information from parents. In this case, information appears as belonging to the informational self-determination of the child as future adult. **Therefore, the future child's personal consent as an adult takes precedence over the potential actual parental choice.** (Borry et al. JLME 2014, 21, emphasis added) ”

### Alternative foundations of right to genomic ignorance in literature:

- **Adults:** indirectly, human dignity (Taupitz 1998. In: Festschrift für Günther Wiese); privacy (Laurie Eur J Health Law 1999); lack of a duty to know (Takala Bioethics 1999)
- **Young children:** open future (Morrissey/Walker J Med Philos 2018); child's privacy (Borry et al. JLME 2014)

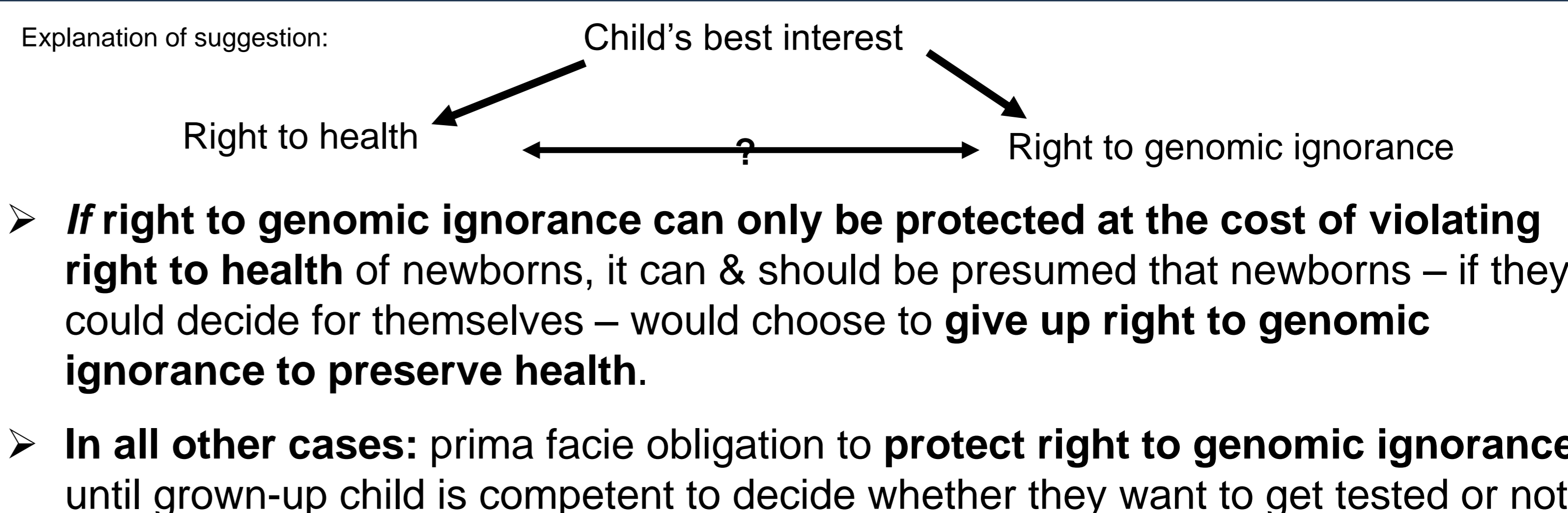
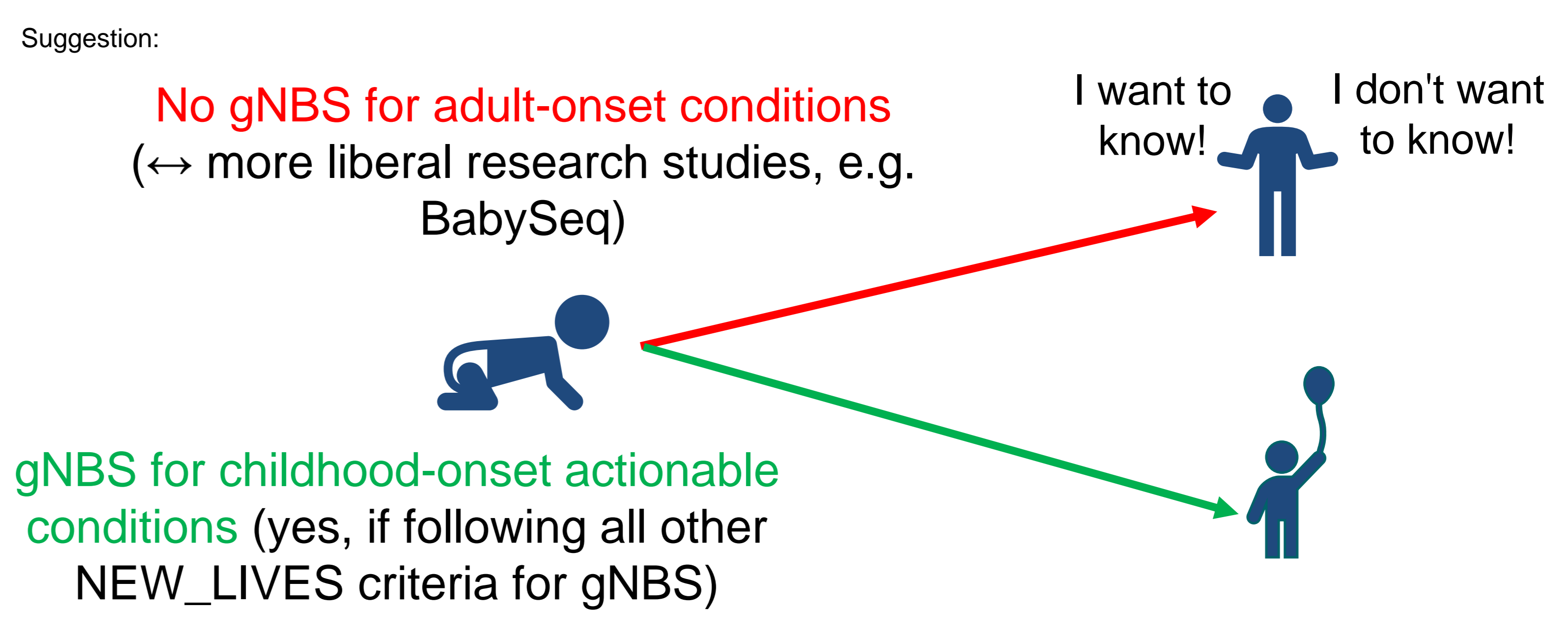
## (3) Conceptualisation of right to genomic ignorance as future & present right of newborns

Freedom (liberty right): Liberty to decide whether one wants to know genomic information or not	Right against interference ("Abwehrrecht"): protection of freedom, others may not interfere (cf. Taupitz, quote below)
<ul style="list-style-type: none"> <li>➤ Future right of newborns (=right of competent minors/adults)</li> </ul>	<ul style="list-style-type: none"> <li>➤ In our view crucial: Everyone (including newborns) holds this right.</li> <li>➤ Associated duties: no genome analysis without consent</li> <li>→ Implications for proxy consent?</li> <li>→ We tend to agree with Borry et al.</li> </ul>

“ Verbot der Informationsermittlung [...] vom (Abwehr-)Recht auf Nichtwissen (als dessen Vorstufe) mit umfaßt [...]. Beispielsweise bedarf schon die **Durchführung** einer genetischen Analyse nicht zuletzt deshalb der Zustimmung des Betroffenen, weil die Kenntnisnahme **ihrer Ergebnisse** erhebliche psychische Belastungen haben kann. (Taupitz 1998, 589. In: Festschrift für Günther Wiese, emphasis in original) ”

## (4) Implications

### of newborns' right to genomic ignorance for gNBS



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