

# **SONGS OF GENOMICS**

HIVE CHOIR

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## HIVE CHOIR

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Lyrics in this songbook were collected from publications related to genomic healthcare and testimonials from individuals who experienced genetic testing within their own healthcare.

Songs of Genomics is a collaboration between HIVE Choir and University of Oxford's Centre for Human Genetics and the Centre for Personalised Medicine.

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# 1. DNA

**Part 1:** Following hand-conducting, everyone sings their own chirpy three-note jingle of 'DNA'. After a few repeats, slow down gradually until jingles loop in overlapping super slow notes.

D N A

**Part 2:** Everyone chooses an amino acid and sings it super slow on repeat. Start to speed up until speaking in fast overlaps. If possible, work towards fast staggered entries in a looping circle.

Alanine	Cysteine	Histidine	Methionine	Threonine
Arginine	Glutamine	Isoleucine	Phenylalanine	Tryptophan
Asparagine	Glutamic acid	Leucine	Proline	Tyrosine
Aspartic acid	Glycine	Lysine	Serine	Valine

**Part 3:** Form two mini choirs.

One choir sings the left text below in an improvised, beautiful polyphony choral style with pleasant harmonies and echoes.

The other choir sings the right text below in an improvised rough homophony choral style.

The left choir begins, and stops when the right choir interrupts them. The choirs interrupt each other a few times before overlapping in cacophony and finishing with the left choir 'so exciting'.

Deoxyribonucleic acid (abbreviated DNA) is the molecule that carries genetic information for the development and functioning of an organism.

DNA is made of two linked strands that wind around each other to resemble a twisted ladder — a shape known as a double helix. Each strand has a backbone made of alternating sugar (deoxyribose) and phosphate groups.

Attached to each sugar is one of four bases: adenine (A), cytosine (C), guanine (G) or thymine (T).

Is there a more amazing molecule than DNA? It makes each of us who we are. The more scientists understand it, the more we all understand ourselves, one another, and the world around us.

We are all far more alike than we are different. In fact, the DNA from any two people is 99.9% identical. The differing 0.1% contains variations that influence our uniqueness.

How can one, single molecule contain so much mystery and wonder? We are only beginning to understand the answer to that question, which is what makes the study of DNA so exciting.

*(National Human Genome Research Institute)*

## 2. The Future of Healthcare (an executive summary)

Sing *The Future of Healthcare* text in 60's Tom Jones, Lulu, Petula Clarke melodies. Individuals lead paragraphs, others can hop in to harmonise and echo.

- *Soloist Call*: The Future of Healthcare

- *Group Response*: Genome UK

- *'It's Not Unusual' Bassline*: Doo, Do Do

Executive Summary published by the Conservative Government. We now find ourselves at a tipping point. The cost of genetic sequencing is falling. It's quick enough to inform clinical and critical care.

- *Soloist interrupts doo's*

This strategy sets out an ambitious and compelling vision for the most advanced genomic healthcare ecosystem in the world.

- *restart doo's*

We are committed to a future where genomics improves the well-being of millions worldwide.

We must take advantage.

- *finger conduct*: BOLD STEPS

- *finger conduct*: WE WANT

- *Boys Call / Girls Response*:

Latest scientific advances / Faster diagnoses

Earlier detection / Target interventions

The full might of R&D / At a Lower Cost

Big health data systems / Data Data Data

- *finger conduct* - WE WILL PROGRESS

- *finger conduct* - WE WILL INTRODUCE

- *finger conduct* - WE WILL BE THE FIRST

- *Sing to 'Downtown' Pre-chorus* ("Listen to..."):

A complementary ecosystem with global alliance/

Machine-Learning, Artificial In-telligence /

Industrial Growth / Entrepreneurship & Funding/

Start-ups & Standards & Innovation, Analyyyytics/

Procurement, Partnerships, Maxi-/

Maximum impact

- *riff to tune*: Impact, impact

- *riff up a tone*: We will engage (x2)

- *riff up a tone*: We will create (x2)

- *riff up a tone*: We will need (x2)

- *drift up a tone*: We will always (x2)

~ *scared whisper*: global pandemics

~ *scared whisper*: threats to public health

- *'It's Not Unusual' Bassline*: Doo, Do Do

- *Sing to melody of 'It's Not Unusual'*:

Also some challenges, in particular around /

with data sharing and equity of access /

We will ensure that our approaches are /

anchored o-o-o-on / (*Stay on low 'doo's*)

Equity-of-access / Measures of success /

Monitor progress / Specific targets /

Data security / And Privacy /

Responsibility / Transparency

~ *confused talk*: responsible, transparent

- *conduct one note*: Long-term ambitions

- *conduct one note*: Delivering on this vision

- *conduct one note*: Exciting and

- *conduct one note*: Compelling

- *conduct one note*: Vision for the future

### 3. Immortal Data

**Group A:** Some sing in plain chant, some in choral polyphony style ('Miserere', 'O Care Thou Wilt Despatch Me'). Listen and echo each other in overlapping lines.

**Group B:** Sing 'Data' following hand conducting.

**Group C:** Very slowly speak the letters of Genetic Code in sync. Start after Group B's first 'Data'. After a while, slowly get faster, then transform to singing letters, then slower to long drone letters. Then slowly morph back to speaking letters very slowly. After Groups A & B have finished, speak a few more letters, then finish.

**Part 1:**

First Group A:

Genomic data do not change  
across the life course  
they are immortal data

Then Group B: Data

Then Group C begin.

**Part 2:** Group B & C continue while Group A sings:

From this immortality arises new  
ethical challenges. The myriad of  
possible future interpretations  
Responsibility to past, present and future

Patterns of inheritance. The familial nature  
of results. Data living on through other family  
members. Heritable risks to future generations.  
Future benefits.

Direct-to-consumer companies have financial  
incentives. Genetic exceptionalism.  
Consent and confidentiality. Data as a collective  
resource.

Anonymised and everything. They kept saying,  
he'll just be a number, he won't be, nobody will  
be able to identify him, not that I'm worried.

**GENETIC CODE:**

taaacttcatggcataaccttgccaaagtataactaagaataaccctgacacaaagctcttttttcagccaacatgccatgaaagaaagaagac  
aaggggtgatctccactctctaagtgaaccactaaaccaccaaagaagaaacgagggaaatagaaagaggacccttgccctgagataatggat  
ctgtatgtatgagtagtagaaccctgctcaaagtacaaaggaagggaaaaaaaagttagtttatttggaattttggacattaagagtctttat  
tgttcattttcttttaactcacatgaatggcttatcacttcaattaataaatatttcatttcttttcaacatattcatgaaacaaatctgaaa  
tgaacagtgcaacatgtgaatgtttagaacattataaaattaaacacaaaatctgtctggcaatcttcctagcatcttaggaaaaaagttgac  
aaaatttcaagcagcagaagggggcagtaaaactcaacagaaagctctggaagatttttaagattcttccttattttcttttcatgtagatta

## 4. Unexpected Information

*Part 1: Everyone starts with a loud synchronised 'Shush!', then continuous 'ssh'ing in soft waves.*

*Part 2: One at a time, people start reading lines of their choice in a slow, relaxed, somewhat melodic voice whilst others remain 'ssh'ing.*

*Part 3: After the whole group has been reading together for a while, the first reader starts 'ssh'ing again. Then, one at a time, everyone starts 'ssh'ing again.*

*Part 4: After the whole group has been 'ssh'ing for a few seconds, someone hand-conducts the ending as either a volume swell or a fade out.*

They've all got children and grandchildren.

I've got three other grandchildren that could be affected.

Both my parents died of cancer.

So it would be useful and interesting to know whether I've got any susceptibility to that from them.

It didn't really feel like there was a choice for my parents not to get sequenced,  
it sounded like it was a thing that had to happen.

I would want to tell my relatives.

Clinically relevant unexpected information.

Women feel an obligation to manage genetic risks in their kin.

As willing to share their own result as they were to receive a relative's.

A 'right of veto'. The 'right not to know'.

As far as I can see, all the benefit's going to be for the wider family.

The potential for infringing a 'right not to know'.

It's not for the people that we know about, it's the people that we don't know about yet.

## 5. A Needle in Pandora's Box

Everyone secretly chooses one of the descriptors below.

**Part 1:** Speak your word in sync with others a few times, then get progressively slower and introduce sung pitches and getting louder.

**Part 2:** Loop your word in slow drones, getting progressively louder until hand conduct climax.

**Part 3:** Speak your words in loops, starting to develop a distinct short catchy rhythm that responds to the meaning of the word. Explore the timing of your pause between loops.

**Part 4:** Develop a meaningful melody for your word and its looping rhythm. Make it super catchy.

**Part 5:** Make your loop more sparse, lengthening your pause so that the group sings their rhythmic melodies in a staggered smattering. Let it breathe for a while, then finish.

Informative

Helpful

Reliable

Predictive

Personal

Problematic

Certain

Context dependent

Unclear

Messy

Worrying

Wildly variable

Scary

## 6. Expectations

A: *Speak health conditions.*

B: *Start humming drones on tonic and dominant, then choose phrases to sing in English folk style (e.g. 'What Would You Do' & 'Here's a Health to All True Lovers'). Turn words into drones.*

Amyotrophic Lateral Sclerosis  
Asthma  
Atrial fibrillation  
Basal Cell Carcinoma  
Breast Cancer

And so, what do you hope to get  
from this project personally?  
I suppose you might say it's a good  
cause to participate in.  
I sat down with someone who was really  
interested in me and explained things to me.  
Such brilliant stuff is going to come from it.

Cardiovascular Disease  
Huntington's Disease  
Sickle Cell Disease  
Tay-Sachs disease  
Colorectal Cancer  
Cystic Fibrosis  
Diabetes

I've donated my blood, and I think they took  
a sample of the cancer, and that's fine.  
If it helps someone further down the line.  
We had to do it a third time.  
And then we waited about three years,  
which felt so long.

Fragile X Syndrome  
Friedreich's Ataxia  
Frontotemporal Dementia  
Gallstones  
Glaucoma  
Gout  
Hemoglobinopathies  
Hereditary Hemochromatosis

False hope. False expectations.  
You can't just keep blindly testing her.  
It's not fair on her.  
Five years and still waiting.  
We were at the bottom of a list.  
When are we going to find out? I need to know.  
I've learned that I have to chase everyone and throw  
my weight around to get things done.  
I just think that the system is so absolutely  
unacceptable, its just like catastrophic.  
  
*~ Stop droning*

High Cholesterol  
Hypertension  
Hypothyroidism  
Infertility  
Malignant Melanoma

I'll leave it to the researchers to use as they want.  
I'll leave it to them.

*~ Start droning again*

I'd much rather know, you know because your  
imagination is always worse than reality.  
So I think that's the best we can hope for.

He pretty much told me that you won't hear anything  
back from the project at all.  
They don't seem to be thinking about real human  
lives, approaching all of this as a research problem.  
I honestly would rather have never known.

Osteoporosis  
Ovarian Cancer  
Prostate Cancer  
Spinal Muscular Atrophyexternal  
Testicular Cancer  
Thalassemia

They're just going to keep testing  
aren't they?

Would it be okay to keep testing?



## 7. Sure / Unsure / Prefer Not To Say / Other / None of These

A: Sing bassline 'bum, bum-bum', like 'Best of My Love' (IV, III, II, I; e.g. F, E, Dm, C) ~100bpm. Sing Chorus in same melody.

B: Sing participant quotes in an r'n'b vibe. Echo and develop others. Sing Chorus with Group A.

C: Speak narrative text from publications (in a newsreader voice)

So there was always this question.  
God, do we want to know?

Double-edged hope.  
Probable possible diagnosis.

We contend that such genetic risk scores are only weakly predictive and using them prematurely in clinic may create more problems than it solves

*Chorus:*

- Adenine
- Cytosine
- Guanine
- Thymine

And you know, I don't know.  
I think I was definitely quite naïve when I started this journey.

Left me a little bit more cynical.  
I'm not sure I want to know that.

I did read all of the stuff at the time, and I can't really remember what it says, but I'm not too concerned.

I think I would have freely consented to that, why not, you know. I don't know really.

"I trust you, you're professionals"

We argue that the problem of false positives here deserves attention. More people will be swept along a pathway of ultimately unnecessary invasive investigations, while a small number will be falsely reassured.

- *Chorus*

I hadn't even thought of the wider blood relatives. Just kind of initially you think of yourself.

It's only you speaking about it now that I actually stop to think about it.

We expect everything to be definitive, you know, there has to be an answer for something.

- *Chorus*

I don't remember what the additional findings were to be honest.

I don't remember, maybe I didn't understand it completely.

I don't remember much, and I don't understand everything, but that's OK.

But I agreed to it.

- *Chorus*

- *Chorus (quiet)*